MAINE STATE LEGISLATURE

The following document is provided by the

LAW AND LEGISLATIVE DIGITAL LIBRARY

at the Maine State Law and Legislative Reference Library

http://legislature.maine.gov/lawlib

Reproduced from electronic originals

(may include minor formatting differences from printed original)

2013 Annual Report

of the

Maine Developmental Services Oversight & Advisory Board

December 30, 2012 - December 30, 2013

Maine Developmental Services Oversight & Advisory Board

Annual Report
2013

Table of Contents

I. Executive Summary.....3

II. Introduction.....5

III. Priorities and Recommendations.....6

IV. Appendices

Appendix A: ***MDSOAB Activities during 2012-2013***.....16

1. The Volunteer Correspondent Program
2. Annual Public Feedback Forum
3. Participation on Three-Person Review Committees

Appendix B: ***Annual Public Feedback Forum Report***.....20

Appendix C: ***Maine Developmental Services Oversight and Advisory Board Membership***.....33

Maine Developmental Services Oversight and Advisory Board (MDSOAB)

Annual Report

I. Executive Summary

We respectfully submit this annual report to the Joint Committee on Health and Human Services, DHHS, and the Governor, January 9, 2013. This report details the oversight activities of the MDSOAB from December 2012 to December 2013, and includes recommendations for action on each of our five identified priorities.

The MDSOAB bases information for this report on data supplied by the Department, anecdotal notes of our work and from collaboration with others during the year, and comments from the 2013 Annual Public Feedback Forum. The MDSOAB collaborated with the Department and SUFU, Maine DDC, Maine DRC, and CCIDS to hold a series of Public Feedback Forums in August. Comment was invited via live forums and through an online survey.

Priority Questions include the following:

1. *How has DHHS/OADS Restructuring impacted the efficiency and effectiveness of the Support System?*

2. *How thoroughly have changes in systemic rules, processes, and services been considered and conveyed?*

3. *How is the Department using data to inform policies, procedures, identify systemic issues, ensure quality and availability of services?*

4. *How can Maine improve monitoring use of intrusive procedures and safety devices (3PCs) for its citizens with ID/ASD?*

5. *What is our progress toward making Maine's support into a flexible, responsive system that is oriented toward levels of support rather than hours of treatment and therapy?*

Recommendations include

Priority 1: OADS Restructuring

- Review recruiting and hiring process to ensure that new positions are clearly outlined, that new staff have overlap time with departing staff when possible, and

incoming staff have clear guidelines and resources to assume their new duties as smoothly and efficiently as possible.

- Give OADS management staff enough time for both internal and external consultation.
- Use communication technology to share information and invite comment. Make sure all formats are accessible.

Priority 2: Impact of Systemic Changes

- Translate the OADS Vision Statements to a long-term timeline with action steps.
- Before instituting major policy or procedural changes, clarify intended outcomes, create ways to assess impact of the change, and consult with experts outside the Department to identify potential hidden costs or conflicts.
- Create or revise the vetting process to assess every potential new contractor hired to address systemic change. Communicate with colleagues in other states about their experiences with the contractor.

Priority 3: Use of Data

- Identify the kinds of data needed to assess need and evaluate progress. Collaborate with other state agencies (i.e. Department of Education) to obtain data that the Department currently lacks. Develop a schedule for reviewing data on an ongoing basis.
- Use more than one assessment source to inform major decisions about major systemic changes.
- Begin exploring alternatives to the current Enterprise Information System.

Priority 4: Monitoring of Intrusive and Safety Procedures

- Finalize and adopt the proposed Behavioral Regulations.
- Provide ongoing training for case managers and others responsible for documenting in EIS.
- Explore ways that other states support individuals with challenging behavior. Identify strategies that Maine might adopt that could decrease the number of intrusive plans.

Priority 5: Progress Toward Flexible Supports

- Translate OADS Vision Statement into a long-term map with timelines and benchmarks of progress.
- Use Vision and plan to guide decisions about changes in services.
- Continue inviting public comment and collaborating with those outside the Department when exploring, developing, and implementing changes in services or policy.
- Develop a clear, concrete method to prepare systemically to support youth transitioning to OADS services.

II. Introduction

The Maine Developmental Services Oversight and Advisory Board (MDSOAB) is charged with oversight of all Maine services and supports for adults with developmental and intellectual disabilities (mental retardation) and autism. We submit this annual report to the Commissioner, the Governor and the Joint Committee on Health and Human Services in partial fulfillment of our charge to provide an overview of concerns for and systemic recommendations regarding "policies, priorities, budgets and legislation affecting the rights and interests of persons with mental retardation or autism." (34-B MRSA §1223 8. B.)

The MDSOAB is comprised of individuals with intellectual disabilities and autism, family members, disability advocates, service providers, and community members, and employs an Executive Director and Volunteer Correspondent Program coordinator.

This report details the Board's priority focus questions, recommendations, and concerns related to systemic policies and practices impacting services for Maine citizens with intellectual disabilities and autism. This report is informed by the Board's work on various collaborative committees and work groups during 2013, as well as by comments from the Public Feedback Forums and online survey conducted in August 2013.The Board focused primarily on the Office of Aging and Disability Services this year.

This report includes an overview of the Annual Public Feedback Forum, and a list of MDSOAB members and MDSOAB activities during the period of this report.

III. Priority Questions

1. How has DHHS/OADS Restructuring impacted the efficiency and effectiveness of the Support System?

Restructuring continued during this report period, with remaining staff positions eliminated or combined and numerous experienced staff who retired, resigned, or moved to new positions. Outside consultants or contractors were hired to help the Department develop new procedures (i.e. HSRC with the Supports Intensity Scale) or implement parts of existing programs (i.e. APS Healthcare for Section 21 Waiver utilization review).

OAB commends Department staff for their flexibility and commitment to keeping daily processes going while meeting responsibilities of unfilled positions in addition to their existing responsibilities. A number of these staff members were, at the same time, working internally to create a new structure to replace the old. We understand that restructuring a large system like DHHS is a messy, labor- and time- intensive process.

Restructuring created fluctuating staffing levels and burdened remaining, seasoned staff with competing responsibilities. During the year, Developmental Services staff was expected to (1) maintain existing services to consumers, (2) establish or rebuild communication outside the Department, (3) meet internally to help redesign the system, and (4) assume work from unfilled staff positions. Added to this was the need to orient new staff. Most incoming staff seemed to spend at least one month with overlapping jobs (maintaining their current position while assuming responsibility for their new position) rather than having any overlap with the person they replaced.
We commend OADS management-level staff for doing their best to address all these competing demands. There is a point at which an organization can become too lean to to maintain, let alone increase, efficiency, and there were times that OADS seemed close to this point. Clearly, the Department must keep enough experienced, knowledgeable staff members to maintain the existing structure while making carefully considered strategic decisions about a more effective new structure.

Communication and collaboration between the Department and external groups has improved in some ways, and was less effective in others. Developmental Services (DS) staff participated in meetings with outside individuals and organizations, and external organizations were invited by DS staff to participate in systemic change initiatives with representatives of other organizations. We observed an opening of some collaborative channels during FY 2013.

Communication and collaboration was also slowed or lacking, at times, as restructuring continued. Some changes seemed instituted without adequate advance notice (i.e. the closure of the dental clinic and changes in transportation, which will be discussed later) while other proposed changes appear stuck in a holding pattern (i.e. adoption of the proposed behavior regulations, which were drafted more than three years ago). Status reports about things like wait list numbers, crisis bed usage, and other internal data

were often not easy to get. This created a particular problem for the OAB, as we use the data in our oversight function. This access seemed to improve recently, although remaining holes in the data continue to make it difficult for us rely on the data as a resource to provide meaningful oversight.

Priority Question 1 Recommendations:

- **Before the restructuring process is complete, carefully assess** the work associated with each remaining or newly created position to ensure that it is sustainable and realistic for one person to manage. The Department cannot afford to lose any more seasoned staff members if it hopes to increase both efficiency and effectiveness. Yes, fewer staff means less overall cost- but it also can mean that overall work is lower in quality and slower in movement.

- **Give key OADS staff time** to consult with each other and to create a more streamlined process for communicating and working with those outside the Department. Staff members also need time to respond to requests from others outside the Department. This is not to suggest that staff members are currently unresponsive; rather, we suggest they need more time between meetings or events to address concerns.

- **Use communication technology** (i.e. electronic message boards, online webinars and training modules) to share information and invite comment. Using technology like real-time videoconferencing and online asynchronous training modules will lessen the need for staff to attend multiple meetings on the same topic. This could also give more access to participation for people who live at a distance or cannot participate in conference calls. Videos should be closed-captioned, and accessibility options should be built into everything the Department does. There are many experts in Maine who can help the Department build accessibility into its websites and presentations.

- **Address recruiting and hiring people** for new positions, whenever possible, BEFORE the long-term employee retires or leaves employment; ensure that policies and procedures are outlined and easily accessible so that each new employee is reasonably oriented to the new responsibilities. This will ensure that work continues with minimal impact on clients served and their families.

2. *How carefully have changes in systemic rules, processes, and services been considered and conveyed?*

Changes in rules, processes, and services occurred along with changes in staffing. The OAB assumes that the overall vision is to create a support system that is more effective, efficient, and responsive. We also understand that the state, along with the country, is in a financially difficult period.

Given this, we are concerned that some of the recent changes have not been fully vetted for unintended consequences that could result in violations of individual's rights, undesirable impact in variety or responsiveness of supports, or hidden cost. We also wonder if some external companies- notably, APS Healthcare- may have been hired by the Department without careful consideration of their records in other states.

Two examples of changes in services that did not appear to be carefully considered were closing of the dental clinic used by many adults with ID, and the privatization of the transportation network. In the former example, no plan appeared to be in place to fill the void in services that occurred, and capacity in an already under-resourced area was further diminished. Comments from consumers and their family members at our 2013 Feedback Forum and survey series were clear that the consequences of this decision were unacceptable:

> *"Let's talk about the closure of Clinical Services. My child has no dentist. What's happening? The case workers didn't share info with anyone, except that they are going to re-open new offices eventually. There was only one week's notice. Closing without another plan in place is NOT okay.* " (parent, Portland forum)

Statewide impact of privatization of the transportation system continues to be problematic, with consumers missing appointments, work, and programs to which they are entitled because their ride shows up very late, or not at all. One house manager reported

> *Instead of enjoying their day, our consumers are angry and worried they might not get picked up or arrive at a scheduled appointment on time. More than several have been hours late arriving home and they are hungry. Some of their issues and "behaviors" are due to tension but also not eating and being hungry... If more people depended on the city bus system to get to work or appointments and suddenly the bus system stopped working, I think the issue would be fixed almost immediately. Why do the people I support not count as much?*

A parent on Mount Desert Island said

> *...when the ride is late, or doesn't show up, there is no contact from the transportation office, [and] appointments are missed, or another ride can't be found, since we don't know if the ride is coming or not... For our autistic son, and others like him, that creates anxiety because their routine is disrupted, and they are anxious about missing their program and friends, who are very much a part of their lives.*

We are concerned that Maine may lose more money than it saves by hiring private contractors who have a questionable record in other states. For example, the Department hired APS Healthcare to assist with redesigning how services are aligned with support need and, presumably, to achieve financial savings and greater resource utilization efficiency. APS Healthcare has a poor record in other states (i.e. California and West Virginia), and was sued by Georgia for failing to provide services for which it was paid. In Maine, APS Healthcare has demonstrated worrisome communication with individuals and their guardians. We are receiving ongoing reports that APS has imposed a complicated, administratively burdensome authorization process for determining or changing an individual's program hours. This does appear to demonstrate an efficient or effective use of resources.

Finally, we are concerned that information about upcoming changes has not been shared systematically, meaningfully, and in some cases, at all, with those whom it directly affects- adults with ID or ASD and their families.

Priority 2 Recommendations:

- ***Translate the Department's long-term vision for OADS to action steps*** with a timeline, and make this available to the general public. This vision can inform and make visible the reason for each change.

- ***Before instituting a major policy or procedural change, clarify how the proposed change will improve services***- what will be better as a result, and how will you know/measure the anticipated improvement?

- ***Ensure that those with expertise at a variety of points review the proposed change*** and identify potential hidden costs or conflicts before the change is finalized. Include those who will be affected by the proposed change, and those with a nuanced understanding of legal implications and potential rights violations, in this assessment.

- ***Assess impact of the change from its implementation to at least one year after change***. Solicit feedback from those impacted by the change across the state as well as those inside the Department.

- ***Revise the RFP and vetting processes for the selection of potential contractors.*** It is especially important to carefully research the reputation and experience of private contractors, including assessing experiences of those receiving the contractor's services in other states. The lowest bidder is not always the least expensive option when one considers the cost of inefficient or low-quality service.

- ***Before making a major change***, ensure that information about the change has been shared with individuals receiving services and their service providers well in advance. Case managers should receive clear, concise descriptions of proposed changes.

3. How is the Department collecting and using data to inform policies, procedures, identify systemic issues, and ensure quality and availability of services?

From the OAB perspective, it has been difficult to determine what data the Department collects, in what ways and how often it is collected, in what ways it is analyzed, and how it is used to inform the Department's work. If the Department does not generate reports regularly to inform its own process, how can it make accurate projections, fully understand areas in need of further development or attention, or have a clear picture of the current status of services? As noted previously, data and information sharing from the Department, is improving, and some Department staff have done their best to respond to our requests. If OADS administrative staff members have difficulty accessing data or knowing what data is already being generated for other purposes, we wonder to what degree data-informed status reports are used to guide proposed changes.

We note that OADS is actively working to fill one of the biggest holes in their data: that of youth transitioning from CDFS to OADS services. OADS, during the year, reconvened regional collaborative transition teams that include CDFS, OADS, DOL, and DOE personnel. Tracking youth from age 16, especially in collaboration with DOE, which may serve youth in special education who are not in the CDFS system, will help the Department project future needs and hopefully build capacity in key areas. This should also help the Department make more realistic appropriations requests of the Legislature. Finally, it may help smooth the transition from children's to adult services, and decrease the number of youth who "fall through the cracks," finding themselves without a case worker or any idea how to access the adult service system.

The OAB, in collaboration with the Volunteer Correspondent Program, have noticed that ***the Department's EIS data is often out of date*** on various topics and appears not to be updated consistently by case managers in particular. We also are aware that the EIS does not readily interface with other data tracking systems in common use by others in- or, for that matter- outside Maine. This creates a greater burden on the few staff members who are able to access and run reports based on EIS, as they are not only the gatekeepers, but also the translators, for everyone who needs the data.

The outdated nature of the EIS data has significantly slowed the progress of the VCP in meeting the need for correspondents for individuals with ID or ASD. From the OAB's perspective, we are concerned that systems-level decisions based on EIS data may not reflect the actual need. ***There appears to be a need for ongoing training for community case managers and ISCs to ensure that data is current, accurate, and that they are using the same protocols***.

Priority 3 Recommendations:

- ***Identify the different kinds of data the Department needs to assess systemic operations:*** access to services, availability of services across regions and populations; quality of services. For each area, first look to current databases to determine what can be mined for each area, and align data collected with data needs.

- ***Use more than one assessment source*** and more than one type of data whenever possible and especially when considering systems-wide changes or assessing capacity and need across the state.

- ***Compile and share data evaluations*** on a regular basis with the purpose of improving quality and efficiency of services.

- While EIS appears to meet the need at the moment, it may be wise to ***explore databases being used in other states*** (especially states with similar demographics as Maine) to determine if there is a more universal, user-friendly, and comprehensive system available. In the long-term, Maine may want to consider changing over to a different database- and now is the time to begin exploring other options.

- ***Continue to develop and refine the system for tracking youth from age 16 in collaboration with DOE, DOL, and CDFS***. Add this data to decisions affecting appropriations requests, and to build systemic capacity both geographically and in response to various kinds of support needs.

- ***Ensure that each state agency is aware of the goals, definitions, protocols of others,*** and address obstacles that might arise from differences. Because each state-level agency operates from different federal funding streams that employ different definitions, a potential obstacle to effective, efficient planning is the lack of shared definition. ***Train case managers about the different service systems*** and provide ongoing technical assistance to help staff from all systems and at all levels work together. Hopefully, this will help smooth the transition between service systems.

- ***Ensure that those in more direct contact with youth and families*** (for example, DOE, MADSEC, and Guidance Counselor organizations; children's services case workers) are informed about the parameters and procedures of OADS, VR, and other adult service systems. Conversely, train adult service system case managers to understand the children's service system and to collaborate with their colleagues across boundaries.

4: What would it take to improve monitoring use of intrusive procedures and safety devices?

There are individuals served by the system who have behavior management plans that call for temporary restriction of their rights in order to keep them or those around them safe. Parameters of these plans, and of their monitoring, are outlined in the Behavioral Regulations [citation here]. A "new" draft of these regulations was drafted well over 3 years ago, has undergone several adjustments, and awaits approval. The "new" regulations, in part, clarify a number of troublesome or unclear aspects of these severely intrusive behavior plans.

Members of the behavioral plan review committees, also known as Regional Three Person Committees or 3PCs, resumed meeting bimonthly in late November of 2012. This statewide Committee has drafted guidelines and checklists, based on the current regulations, that we hope will clarify the submission and re-approval processes and create consistency across the state. ***Department staff have been actively involved partners in this process,*** and have posted relevant documents on the Department website as they are developed.

We have identified some long-term goals for this Committee:

- Continue to create standardized checklists for providers so that adequate information is submitted for review each time a plan is under review

- Create guidelines for writing severely intrusive plans, and examples of plans for providers

- Begin tracking incidences of behavior plans appearing to result, at least in part, from issues within the provider or Dept. systems, i.e. high staff turnover, inexperienced staff, incompatible housemates to identify themes

We continue to await approval and adoption of the latest version of the "new" behavior regulations. As noted in a previous section, inconsistent input of data into EIS by case managers continues to be an issue that slows down review of many plans, as we cannot rely on the data in EIS to reflect the most current information. As individual 3PC members do not have independent access to EIS, we must rely on providers to remember such things as the date of the individual's last comprehensive psychological evaluation, or occupational therapy or communication evaluation.

Finally, OAB members of these 3PCs continue to wonder if there is a more effective way of addressing the need to keep people safe. We began looking at the practices of other states in this area, but find ourselves without the time and resources to continue this exploration in any depth. There are, however, some promising ideas in states like Oklahoma and Vermont.

Priority 4 Recommendations:

- ***Focus effort on finalizing and adopting the proposed behavior regulations***. Once this is complete, the statewide 3PC can put some effort into creating helpful guidelines for planning teams to use as they consider developing- or reducing the use of- severely intrusive plans for individuals.

- ***Provide ongoing training for case managers and others to ensure that 3PC results are entered into EIS in a timely manner***, and that paperwork part of process is efficient and not unduly burdensome.

- ***Explore ways that other states address the need to keep vulnerable people safe*** while violating their rights as briefly and as little as possible. We do not suggest that any one state will have a procedure that can be adopted in its entirety by Maine; however, several states employ promising practices that could inform a new approach. We would like to see DHHS explore strategies that have been used successfully in other states that might decrease the need for severely intrusive behavioral plans in Maine.

5: *What would it take to make Maine's support system flexible enough to be responsive to the individuals changing needs in both the short- and long-term?*

The Office of Aging and Disability Services charged with two sometimes competing responsibilities: to provide Maine's increasing population of adults with intellectual disabilities, autism, and vulnerable aging people with individualized, community- and home-based services that are responsive, flexible, and that promote autonomy; and to decrease its overall budget. Maine has recently been noted as having the "oldest" population; and Maine, like every other state, has seen a stark increase in the number of children and adults identified with autism. Presumably, the need for services will continue to increase.

OADS, in response to the LD 1816 directive to "increase efficiencies" in a number of areas, formed a work group of stakeholders to craft recommendations with the Department. This group completed its initial task in the summer of 2013, and continues in a different form to serve as a resource for the Department.

The Department also crafted a series of long-term vision statements and invited public comment on this vision during the Annual Public Feedback Forum series in the summer. This vision is an important first step toward grounding the system in a central philosophy that can be a foundation guiding future systemic change. Without this, the Department might continue to be driven toward reactive changes that, in the long-term, contribute to the disconnection and inefficiency of the system as a whole.

Finally, the Department demonstrates an ongoing commitment to decreasing the wait lists for services by seeking to broaden the parameters of the Section 29 waiver. This waiver, with the addition of key supports, seems likely to become the primary support system for adults with less intensive support needs.

We are now experiencing the negative effects of past policy changes that resulted in the creation and explosion of the service wait list several years ago. The long-term costs of being on the wait list for several years are, for the individual, loss of skills and, often, deterioration of physical and mental health.

There is a great cost to family members, too, as parents of those on the wait list are often expected to support them. Many find they must leave the work force, losing their source of a living wage, and are forced to use their retirement savings to keep the family afloat. Their adult children often are not given a high priority for receiving services unless they are in danger of or actually become homeless, or are a risk to self or others. This leaves the system in a constant mode of reacting to immediate crisis, instead of planning for the long-term, and leaves folks languishing on the wait list until a crisis develops.

Could there be a way to choose individuals from each priority level, which might result in fewer names overall on the wait list and less deterioration in the individual's skills and health? Some on the Section 21 waiver wait list currently receive Section 29 waiver services. The expansion of Section 29 services may be an important first step toward a more equitable, responsive service system, since at least some people currently on the Section 21 wait list may be able to get their needs met under the expanded Section 29 waiver. We wonder if there be a way to reserve at least some Section 29 waiver slots for youth who are exiting school.

Priority 5 Recommendations:

- ***Use the OADS Vision statement as a starting point to map benchmarks and timelines.*** Identify statutes, policies, and procedures that will need to change in order to move toward the vision.

- ***Continue to explore new ways to open services to those on the wait list, and alternatives to the current waiver funding selection system.*** It will take time- and funding- to shift from only being able to respond to the individuals with the biggest crisis, to providing everyone with a level of service that, at the very least, keeps them from losing skills, health, and family support while they wait for services.

- ***Continue collaborating with others*** who can help shape the emerging service system. OADS staff should be commended for their willingness to bring others into the re-visioning process, and to collaborate with others to invite and respond to public comment.

- ***Explore ways that Maine, at one time, addressed the needs of youth in transition***. At one time, Maine led other states in its network of transition resources. The Maine [Transition] Resource Network's work in the mid- 1990s outlined a comprehensive, specific approach, with resources to address the needs of youth in transition, their teachers, and their families. These materials can serve as a foundation for developing an updated approach, with DOE, to supporting Maine's youth in transition.

Appendix A

MDSOAB Initiatives

1. The Volunteer Correspondent Program

The MDSOAB operates the Volunteer Correspondent Program, which began in 1978 to pair Pineland Consent Decree class members who lacked active family involvement with a volunteer to spend time with them, monitor their progress and supports, and advocate informally for them when needed. This program is now open to any adult who lacks a private guardian or family member who is involved in his or her life.

During the past year, an ad hoc group formed to draft legislation that would establish a successor to the current Volunteer Correspondent Program, or VCP. The proposed program was intended to operate independent of the MDSOAB, with its own advisory board and, eventually, its own funding. The VCP Coordinator assisted this ad hoc group by providing administrative support, updating the list of active correspondents, and mailing a survey to current correspondents that asked about their current level of involvement and their needs for ongoing training and support. The VCP Coordinator compiled all survey results for the committee, and is also using the results to inform training modules currently in development.

LD 897, An Act to Create an Independent Volunteer Advocate Program, was vetoed by the Governor last spring. Aspects of the ad hoc group's work continue to inform the existing program, and provide a blueprint to guide the continued development of the Volunteer Correspondent Program.

The work to support the LD 897 Ad Hoc Group also made visible some problems with the Department's Enterprise Information System, or EIS, including:

- Outdated case manager contact information
- Outdated consumer information (address, telephone, provider contact- and, at times, deceased consumers were still listed in EIS as living)
- Outdated or missing correspondent name or contact information
- Incorrect unmet need for correspondent information

The VCP Coordinator has been working closely with Lisa McGrath from OADS to identify and address incomplete or incorrect information; however, since case managers are responsible for updating information, neither the VCP Coordinator nor Lisa McGrath can input the correct information. The correspondent information in EIS remains sadly outdated and of little use, at present.

The VCP Coordinator has been denied access to EIS with DHHS restructuring, although the program's previous coordinators used EIS as an ongoing and key part of their work. This lack of access slows correspondent progress considerably, since the

coordinator must spend time tracking down new case managers, new contact information for correspondents, and must rely on case managers to return her calls or e-mail messages.

The VCP's growth, at present, is also slowed by the lack of access to background checks for potential correspondents. The VCP carefully reviews the suitability of each applicant, including his or her driving, criminal, and adult protective records (if any exist). The Office of Advocacy accessed these background checks for the VCP prior to summer 2012, and the DRC provided them until April 2013. We currently do not have a contact person in the state system to provide these background checks; nor do we have adequate funds in our budget to request them directly (each background check costs $25.00). The OADS Program Manager has been working to identify a way for the VCP to resume accessing background checks, but no solution has been offered yet. We have been unable to appoint any new volunteer correspondents since May of 2013.

- ***Consumers who have a Correspondent: 309.***
- ***Consumers who need a Correspondent: 167.***
- ***Appointed Correspondents: 246.***
  Some correspondents are matched with 2 or 3 consumers.
- ***Correspondent/consumer matches finalized in FY 2013: 35.***
- ***Correspondents awaiting appointment: 30.***
  Again- we are currently unable to appoint correspondents until a source for background checks is identified.

2. MDSOAB Participation on Three-Person Review Committees

Members of the MDSOAB participate as community members on the Three-Person Committees that are charged with reviewing and approving every severely intrusive behavior plan and safety device plan in the state. With the recent turnover in OADS staff and the replacement of DHHS advocates with DRC advocates, we often find ourselves to be the senior members on these committees. As outlined earlier in this report, MDSOAB members continue to work with the Department and the DRC to create more standardized review practices across the state, to create guidelines to assist providers who submit plans for review, and to prepare for the eventual adoption of the proposed behavior regulations.

Safety Device Reviews during 2013: 324 plans

The current regulations call for the review of safety device plans at least once per year. Safety Device Plans are written for any mechanical device that restricts an individual's movement in order to keep them safe. Examples of safety devices are seat straps for shower chairs, padded bed rails, and gait belts for those with balance problems.

***Severely Intrusive Plan Reviews in 2013:* 127 plans, 411 reviews**
Severely intrusive behavior plans are created for an individual whose behavior escalates to the point where the individual or those around him or her are in danger. Severely Intrusive behavior plans involved the planned use of interventions that involve a degree of coercion and temporarily limit that person's rights. They are created by the individual's planning team with participation from a licensed psychologist or psychiatrist. The psychologist or psychiatrist monitors the implementation and effectiveness of the plan at least monthly once a plan is in place. The Three Person Review Committee, or 3PC, reviews proposed plans for documentation of prior attempts to address the maladaptive behavior through less intrusive measures and takes all possible steps to protect the health, safety, and rights of the individual, and that the plan is clear and comprehensible to all its users. Once a plan is approved, the 3PC reviews it at least quarterly to ensure that it conforms to the standards named above and that it continues to be the least intrusive intervention possible. Three Person Committees typically meet at least once per month to review plans, with the Portland and Lewiston teams having the greatest number of plans and Aroostook having the fewest.

3. The 2013 Annual Public Feedback Forum

Public feedback forums were held August 2013 to invite comment on state-provided or funded support services for adults with intellectual disabilities. Forums were held in Augusta, Bangor, Ellsworth, Farmington, Portland, and Presque Isle. A separate online survey for service recipient input was offered for two weeks following the forum series.

The forum and survey series was a collaboration between the Maine Developmental Services Oversight & Advisory Board and the Developmental Disabilities Council, Disability Rights Center, DHHS Office for Aging and Disability Services, Speaking Up for Us, and the University of Maine Center for Community Inclusion and Disability Studies.

See Appendix B for Annual Public Feedback Forum Report.

4. Other Maine DSOAB work included:

- Participating on the LD 1816 Work Group, which drafted a vision to transform the current service system for adults with ID/ASD

- Monitoring proposed legislation affecting adults with intellectual disabilities during the 126th Legislature's first session, and collaborating with other constituent groups to provide public comment

- Providing assistance to the Volunteer Advocate Program Ad Hoc Group, who wrote and submitted a bill to the legislature to transform the existing Volunteer Correspondent Program to an independent program

- Collaborating with DDC, DRC, OADS, CCIDS, and SUFU to plan and carry out the Annual Public Feedback Forum

- Analyzing Forum results and drafting the Forum Report

- Collaborating to reconvene the Statewide Three Person Committee Group, which met bi-monthly to review procedures, create guidelines for plan submission, and discuss ongoing issues affecting Severely Intrusive and Safety Device Plan review

- Participating on the Proposed Behavior Regulations Work Group to rewrite the proposed regulations to reflect the new 3PC structure

- Monitoring and commenting, when needed, on changes in policy, personnel responsibilities, and practice resulting from the DHHS restructuring

- Providing ongoing feedback to Department staff and identifying systemic issues we find as part of our analysis of data

- Providing comment and recommendations about ongoing practices that need to be changed, or changes in practice that could have unintended and negative consequences for individuals who rely on MaineCare-funded supports in their daily lives

Appendix B

The 2013 Annual Public Feedback Forum

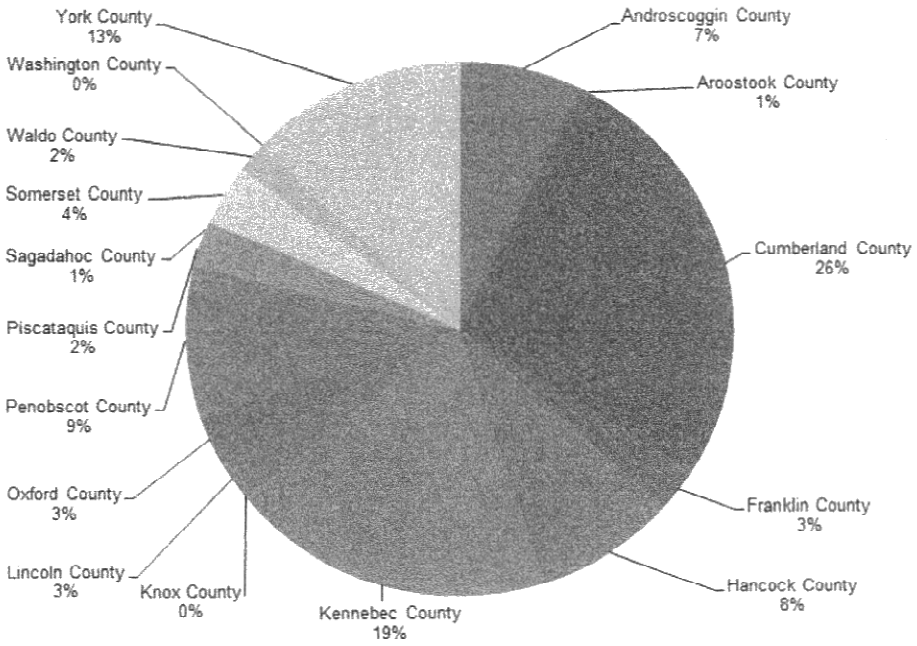
Public feedback forums were held August 2013 to invite comment on state-provided or funded support services for adults with intellectual disabilities. Forums were held in Augusta, Bangor, Ellsworth, Farmington, Portland, and Presque Isle. A separate online survey for service recipient input was offered for two weeks following the forum series.

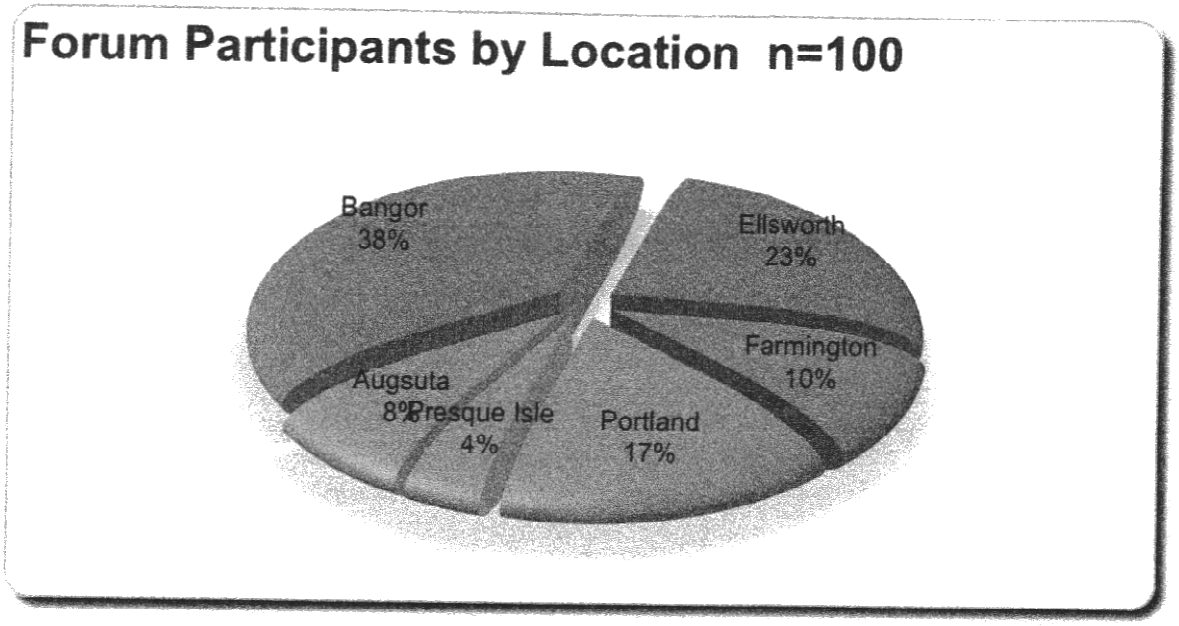
The forum and survey series was a collaboration between the Maine Developmental Services Oversight & Advisory Board and the Developmental Disabilities Council, Disability Rights Center, DHHS Office for Aging and Disability Services, Speaking Up for Us, and the University of Maine Center for Community Inclusion and Disability Studies.

Forum and Survey Participants

Public forums were attended by approximately 100 people. Ninety-six people responded to some or all of the online survey.

SURVEY Participants by County
N=96





What Did We Learn?

Several topics emerged from the forum and survey outcomes, organized for this report as:

1. **The Service System**
2. **Finding and Using Services**
3. **Waiting for Services**

Participation in both the survey and the public forums was limited, and there was low participation by individuals who use the services, both of which may limit the generalizability of the outcomes in this report. In the absence of any other systematic gathering and sharing of information, however, the responses of those who participated in forum and survey should not be dismissed entirely.
The outcomes can serve as a look into the system as experienced by some individuals, their families and friends, and support staff, suggest concrete areas in need of improvement, and will help identify topics explored in the 2014 forum and survey effort. What follows is a summary of outcomes by topic. To see the complete survey responses and forum discussion topics, please see http://www.mainedsoab.org.

1. The Service System

Finding and advocating for services continues to be an area of concern for people with disabilities, their guardians, and their allies. By "service system," we mean any service offered by a Maine state agency or any service paid for by MaineCare. State agencies include DHHS, OADS, Department of Labor Vocational Rehabilitation (VR), and Social Security. Services include community case

management, home and community-based supports, job development, transportation, and advocacy.

Communication with the Service System

People wanted information from OADS shared regularly. They requested that notification well in advance of proposed changes in services, and prompt responses to questions asked and results of public comment. State agencies like Voc Rehab and statewide providers like the DRC were asked to better publicize who they are, what they have to offer, and how to contact them.

- **Access to resources needs enhancement**. *"It would be wonderful ...to get the information to parents in simple terms, know what is available. I don't know of any parent who is really comfortable dealing with that [service terminology] ... I would like to have a "cheat sheet" that minimizes legal language."* (parents, Augusta- with agreement from other parents) While some of these "cheat sheets" may already exist, they may not be available in easily found places.

- **Resources need to be more accessible**. *"In dealing with the Social Security Administration, there are a variety of policies and rules... when they hand that to me, it seems like it is in another language.... I need information that is not filled with acronyms... English isn't my primary language."* (service recipient, Bangor)

- **Online communication is difficult for people in some parts of the state**. *"We have people who don't even have dial-up...technology access can be an issue."* (parent, Presque Isle) *"We don't use the Internet..."* (parent, Ellsworth forum)

Case Management

Maine has a largely privatized community case management (CCM) system, with a few state-employed individual service coordinators (ISCs). **Responses to the online survey suggested that most individuals with disabilities seemed, overall, satisfied with the case management services received**. A majority of those who responded know who their case manager is, believe case manager is helpful, talk to their case manager for help, and learn of changes in services from their case manager.

- Survey and forum participants stressed the importance of a well-informed, well-organized case manager: *"Our son's transition was fairly easy with the help of a good case manager."* (survey participant)

- The most frequent criticism of case managers was a lack of responsiveness from some case managers. *"Case managers not bringing info to meetings. Case managers [are] not attending most meetings."* (survey participant)

- Many participants expressed frustration at having a case manager in name only: " *Technically I have a case manager, but she never shows up. It's the first time ever, since he was born, that he's not had one..."* (parent, Presque Isle)

- Some noted a problem with frequent case manager turnover: "*We're always dealing with a new case manager. When they change, we have to go through whole process of planning again...".* (parent, Farmington)

Forum participants want case managers to be better informed about things like who they can and cannot serve (i.e. children, adults with ID, ASD, MH) the service system in general, available resources, trainings, and events, writing clear goals with measurable objectives, and how to lead the planning team to develop long-term plans with the service user, and to plan across systems (children's, adult, DD, MH).

Planning

Every person receiving services has an annual plan that is developed with their planning team, and that determines the services and levels of support they receive.

The planning process was not a topic discussed in depth at the public forum, but there were a series of survey questions on the topic. Most reported that they

- know what a PCP (Maine's version of a person centered plan) is,
- attend at least part of their meeting
- know that they have choices about when and where the meeting is held, and who attends
- know at least some of their annual goals, including goals that are important to them and at least one employment goal.
- know that they can request changes in their plans.

- Participants noted that there is a need for individualized planning, rather than " *a 'cookie cutter' or one size fits all program"* (survey participant) or "*services that are not suited for them, only because that is what is being made available.* (survey participant)

2. Finding and Using Services

In general, individuals and their families expressed frustration trying to navigate the service system. Their comments appear in nearly every topic but are especially prominent in case management, employment, health services, and transportation. For the purposes of this report, "services" are those contracted by the state and include advocacy, health services, home supports, day program, getting and keeping a job, and transportation.

Advocacy

A series of survey questions addressed advocacy for adults with intellectual disabilities. Additionally, there were a number of comments about advocacy from both the survey and the forums.

Disability Rights Center (DRC) assumed the role of advocate for adults with intellectual disabilities September of 2012. The DRC publicized this change in advocacy through an outreach beginning August of 2012.

- A majority (86%) of survey participants responding to advocacy questions said they know how to call an advocate, although most had not called an advocate during the previous year.

- More reported knowing who to call for advocacy than reported not knowing whom to call.

- Several commented that they have called their advocate and received no response, the advocate is not always available, or was too busy to help. One survey participant wrote *"Nobody will answer when I call and it's frustrating".*

- Many people wanted more information about how an advocate could help them: " *I don't know what the advocates can do for me. Can they help me with these problems?...I don't know how to find who these advocates are and what they do."* (Bangor service recipient)

It appears that there is a continuing need for publicity about advocacy services.

Health Services

In general, forum participants were concerned about the lack of advance notice, thoughtful planning, and consideration of unintended consequences for changes in medical and dental services, including transportation to and from appointments. (Transportation will be discussed in more detail later in this report.)

- The change in allowable medications was troubling to some.
  - *Medication regulations...generics are creating dangerous hospitalization, loss of job work - Maine is not protecting all citizens [from] this.* (survey participant)
  - *Increase of seizures, people hospitalized, which costs more money in the long run... (Reference to incident in Massachusetts, where people got sick and died from use of compound meds)... Manufacturers aren't required to put full amount of what med is needed, and this isn't being addressed.* (service recipient, Portland)

- Participants believed that proposed changes to services were not communicated clearly enough or soon enough (if at all).
  - *"Let's talk about the closure of Clinical Services. My child has no dentist. What's happening? The case workers didn't share info with anyone, except that they are going to re-open new offices eventually. There was only one*

week's notice. Closing without another plan in place is NOT okay. "(parent, Portland)

- Several people expressed concerns about the lack of adequate dental and medical care in many parts of the state.
  - *Without appropriate health care, you may never know what you really need to treat. Addressing symptoms of illness or pain with behavioral modification techniques will gain a short term response (positive or negative), but eventually lead to a more serious health problem.* (survey participant)
  - *"I wish MaineCare allowed more funding so the dentists could take more. They can't afford to take more because of the low reimbursement."* (sibling, Bangor)

Home and Community Support

Direct Support Professionals (DSPs) provide day-to-day support in home, community, and day programs. They help people learn new skills, provide supervision, and help people access their communities.

- While DSPs are an indispensable part of home and community-based support, they continue to receive low pay for their work. This contributes to frequent staff turnover: *"The more the state squeezes the budget, the less they can pay [direct support staff]. They're not getting much... you spend all that time training them, and two months later they leave, because they found a job that pays better. And ...that's an added stress on [service recipients], they have to change who is providing them support."* (provider, Ellsworth) and " *We pay people at Burger King more than these people who are taking care of the most vulnerable population..."* (parent, Bangor)

- High DSP turnover effects the health and well-being of individuals needing support: "*My support system keeps changing it is very hard for me to become trusting in the new person."* (survey participant) and " *There is already enough insecurity in having to rely on other people and to not know if the people you rely on are going to be there for you when you need them is extremely scary."* (survey participant)

- Participants noted that DSPs are sometimes ill-prepared to support the people they serve: "*Staff sometimes make offensive comments while in the presence of consumers...One time a staff person called me fat and lazy. It frustrated me.."* (consumer, Portland)

Day Program

Thirty survey participants reported attending day program. Overall, they reported that they learn new skills and participate in enjoyable, meaningful activities at day program. Most reported having "the right amount of hours" at day program, while some would like more hours.

- Participants want VR to have realistic goals for their employment. *"I'm only working for 3 hours, my job coach has been looking for six months already, nothing has come out of it, and my [VR] case is about to close...Voc Rehab thinks that 3 hours a week is a job...I don't think that's a job!* (service recipient, Portland) and *"You go to VR, they get you 2 hours of work per week and they're done. That's okay?"* (parent, Ellsworth)

- Agencies that provide job development and coaching were criticized for hiring staff that appear unqualified for their work. *"We get regular calls from my son's job coach. This job coach doesn't 'get' my son's disability. He's not well informed and yet he gets compensated at a higher rate than people who are better trained.* "(parent, Portland)

- Participants were concerned about employment specialists who have low aspirations for their clients. *"They're not helping me find what I want to do...they're giving me jobs that, normal people won't do what I'm doing now, and they think this is a job here. I'm not happy here, and they don't seem to understand this. ...it doesn't matter to them."* (consumer, Portland)

Transportation

Transportation impacts an individual's access to family and friends, community participation, and employment. Maine has very limited public transportation, and remains a largely rural state.

- Transportation continues to be a major source of frustration to adults with disabilities, their families, support staff, and program staff., *"I would like it if you guys could be more reliable so I don't need to look for alternate transportation and not have high anxiety and nervousness and being able to attend my day program every day early or on time and not being late every day..."* (service recipient, Ellsworth)

- The change to new transportation providers created numerous problems for those needing this service. *" When the transportation company is called you are on hold for up to 1 hour and 30 minutes to talk to some one and sometimes when you finally get a person you get hung up on so you have to start the whole process over... It's a shame that our state is putting outsourcing transportation to save money in front of the needs of our elderly and disabled. "* (survey participant)

- Transportation, or the lack of reliable and easily-arranged transportation was also identified as an obstacle to getting and keeping a job, participating in community activities, and visiting with family and friends. *".. if my son has any problems spending time with people he wants, it is due to transportation issues*" and "*My family has a hard time planning so far in advance - need 2 weeks to lock in transportation...*" (survey participant)

As this report is being finalized, the Joint Committee on Health and Human Services and DHHS, are closely monitoring the transportation problem.

3. Waiting for Services

Maine currently has nearly 850 people on a wait list for Home and Community-Based Comprehensive Waiver (Section 21) funding, and over 450 waiting for Home and Community-Based Waiver (Section 29) funding. In the past year, the Section 21 wait list grew by just over 100 individuals and the Section 29 by just over 40; those on both lists increased by just over 60 individuals. An unidentified number of youth transitioning from children's to OADS services are added to the waitlist each year. The gap between available waiver slots and those needing service grows steadily.

Impact on Families

Supporting an adult with developmental disabilities, particularly for those on the wait list for services, often takes toll on everyone involved. Many of those on the wait lists continue to live with family members while they wait. Ironically, those living with family members are often less likely to receive waiver funding soon because they are less in danger of becoming homeless.

- In the absence of available or adequate services, family members are often unpaid service providers. This takes a toll on families in a variety of ways. "*We have a two-parent family, we're living at a poverty level as well, because we have to care for her.*" (parent, Ellsworth forum)

- Some people have been waiting for funding for many years, especially those with family support. " *We have been waiting for a waiver slot since 2009...For families that are active, involved, manage all the crises etc...our children are not moving up the list of need...*" (survey participant)

- Parents and siblings who support their family member while awaiting funding often must leave the work force, or deplete their savings, to keep everyone safe and cared for. " *I have aging parents, and I'm now taking care of my adult sister. We have to self pay for housing and programming. I was told by my family that Social Security will help to provide.....Is there funding for me, while I wait for waiver money?*" (sibling, Bangor)

- Aging parents cannot retire because they are working outside the home to stay afloat financially, or are working in the home caring for their adult child. "*As far as employment, you should consider aging seniors and include their desire to retire, rather than employed [caring for their adult children with disabilities].*" (parent, Portland)

- Elderly parents express concern that they will no longer be healthy enough to care for their adult child, or that they will die without system supports being in place. "*My biggest concern after hearing about your situation is that something can happen to*

you tomorrow, and what will happen with your sister? Something needs to be done NOW for a back-up plan. "(service user, to sibling caregiver, Bangor)

- Parents' relationships with their partners, other children, and even grandchildren are affected when the system is not able to provide safe, reliable, adequate support for the individual. *"I don't think people realize how much it changes people's lives. Our son, he's not living with us now... We can't have him live with us, it's a risk... I have grandchildren, and they can't even visit. I feel like I lost 10 years with my daughter, and my grandchildren..."* (parent, Ellsworth)

- Parents who must support their child in the absence of services are unable to afford or participate in education needed to earn a better wage or move up in their work setting. *"Many parents want to come to college, and have a child with a disability, it's not possible. They simply do not receive enough support to be able to go to school ... I can't tell you how many parents have started, and had to stop, because they couldn't get the support."* (educator, Presque Isle)

Transition to Adult Services

Participants, especially parents of people on the wait list, were frustrated at the lack of communication between children's and adult services, of easily found information about available services, and the lack of effective transition planning. Many equated being on the wait list to "falling off the cliff."

- Transition planning must include building the capacity of adult services to serve youth entering the system. *"We don't have the services, and, a child with autism, what to do every day, and no end in sight, god, it's just so stressful ...it's pretty bad when you want something bad to happen [to move her daughter up on the priority 1wait lis]t, and...it's just that huge concern, is she gonna be 30 [before she gets services], and I think the part that hurts the worst, is that it was no surprise that my daughter was coming, ...*(parent, E)

- More clarity is needed about available services. "*What is the waiver? My child is signed up for it, but I don't know anything about what it is. It was offered by the case manager, but not explained. How do I understand this?"* (parent, Bangor forum)

- There are too many points of entry and no overlap or sharing of information between these points. *" The application process should only need to happen once. Everyone knows if the person is disabled or not, so I really do not feel it makes sense to pay for each department to make that evaluation..."* (survey participant)

- People in various systems do not seem to know about each other. "*There is a big gap in the school systems. They don't know much about transition to adult services.. The school didn't help prepare me... they just wanted me to graduate.*" (survey participant) and " *Every service we have received has been a fishing expedition. Our case manager doesn't know one thing and someone else does not know another."* (survey participant)

- People on the wait list are in danger of losing their current level of skills, health, and well-being. This ultimately increases their level of support need-and the cost and intensity of their supports. It affects the well-being of their families." *The availability of services is so limited. Individuals with lots of potential are "falling through the cracks" for YEARS, and losing skills. Families are being forced to stay home to provide care, thus putting more strain on the system instead of being able to contribute by working."* (survey participant)

- The lack of communication between systems is confusing. *"[there] should be a collaboration of services so you are not doing the same application process for SS disability, Adult Case Management, MaineCare, Voc Rehab. The consent forms should be shared between departments."* (survey participant)

- Pushing for needed services can be confusing and tiring. "*These people are being put through the wringer, b/c they don't know the system... Because it is outside their comfort zone, are afraid to push... And unfortunately, most people would give up-they're tired....*" (friend, Presque Isle)

Conclusions

Information from the public feedback series, while not comprehensive or representative of the entire population, suggests that the support system should focus efforts on building capacity in several areas.

1. Improving communication in three key areas would greatly improve the efficiency and effectiveness of supports across the lifespan. These areas include communication
   - from the service system to individuals, families, and providers
   - across the service system, especially during transition from one system to another, and
   - among various service systems (i.e. OADS, VR, Social Security, and providers of services like case management, day and employment support, and especially transportation)

2. To increase the quality and effectiveness of the service system, ongoing training should be made available in a number of areas:
   - the responsibilities of various service systems and state provider agencies (to help systems work together more smoothly, case managers and families better understand what is, and is not, available and who is responsible for each service, and to improve transition between systems),
   - for case managers to improve their skills in weaving together services, advocating for their clients, and leading planning teams, and
   - for front line service providers like direct support professionals and employment specialists to improve the quality of their services.

3. Recognizing that money does not, by itself, solve all problems, there is a need for more funding for services. The Department is caught in the situation of having an increasing demand for services while experiencing increased cuts in resources. This puts them in a difficult position, at best, especially since cuts to the ID population have been going on for at least the last five years. More accurate projections of needed funding, and allocations from the state, might improve the quality of support and decrease the number of people waiting for support.

   Some examples:
   - Providing a living wage to those working directly with adults with disabilities could decrease high staff turnover and hiring of under-qualified people to provide home, day program, and job support.
   - Increasing funding to create more waiver-funded slots will help the Department respond to the steadily increasing wait by supporting more eligible adults.

- Increasing the number of waiver slots could decrease the time that eligible adults sit at home losing skills, physical and mental health, and opportunities to live apart from their families.
- Increasing the number of individuals served and decreasing (or eliminating) wait time will allow family members to continue working, maintain savings, or retire from working.

Appendix C

MDSOAB Membership
December 2012-2013

MDSOAB membership has fluctuated during 2013. There are currently ten MDSOAB members; eight who have official appointments from the Governor's office, and two who continue to await official appointment. MDSOAB representatives range from Kittery to Aroostook County and include self-advocates, parents, providers, and representatives from collaborating agencies.

Membership during 2013:

Wendy Wyman Allen (resigned 6/13)
Bonnie-Jean Brooks
Janine Collins
Rachel Dyer (DDC representative)
Linda Elliott
Tyler Ingalls
Darlene MacKinnon
Eric McVay
Stephen Richard
Rory Robb
Laurie Raymond (resigned 8/13)
Cullen Ryan

We sent four new appointment applications to the Office of the Governor December 2012, and resubmitted two of the same applications October 2013. Two potential members left our ranks while awaiting appointment. We await word on the remaining two appointments, and hesitate to recruit new members to fill our ranks and assist with committee work until we know the status of the pending applications. Continued delay in official appointment from the Governor's Office impedes our ability to complete our charge.