Maine Developmental Services
Oversight & Advisory Board

Annual Report

January 2015 to June 2016

MDSOAB Maine Developmental Services
Oversight & Advisory Board
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Appendices

I. MDSOAB Annual Report: Executive Summary

We respectfully submit this annual report to the Joint Committee on Health and Human Services, DHHS, and the Office of the Governor. This report details the oversight activities of the MDSOAB from January 2015 to June 2016, and includes recommendations for action on each of our five identified priorities.

The MDSOAB bases information for this report on participation in various work groups and committees, collaboration with other organizations, public comments and testimony given by the MDSOAB, our own observations, and comments from the 2015 Annual Public Feedback Forum Series. The 2015 Public Feedback Forum is coordinated by the MDSOAB in collaboration with Speaking Up For Us (SUFU), the Maine Developmental Disabilities Council (MDDC), the Center for Community Inclusion and Disability Studies at the University of Maine (CCIDS), the Maine Parent Federation (MPF), and the Volunteer Correspondent Program of Maine (VCP). Comment was invited via live forums in Houlton, Biddeford, Brunswick, and Norway, and through online surveys developed for individuals, family members, guardians, or correspondents, and providers (including administrators, case managers, and direct support professionals).

Recommendations include

- **OADS Communication**: Allow OADS to have control of their web page contents and layout; ensure that information is presented in a variety of accessible formats, is updated regularly, and includes names and numbers of key OADS personnel. Ensure that information from OADS is current and consistent across district offices. Finally, improve responsiveness to questions, requests, and comments from those outside the Department.

- **Adult Protective Services and Crisis Services:** Increase staffing of both services and improve responsiveness to questions or concerns from the field. APS should decrease the time between receipt of Reportable Event and start of investigation, and resume sharing written reports as directed in statute. Crisis Services, with adequate staffing, could increase use of proactive strategies and develop trainings for providers. Separate the Developmental Services and Mental Health call-in numbers and staff so that those calling in are directed to the correct office.

- **Guardianship:** Work with others to develop alternatives to full guardianship. Separate public guardianship from DHHS oversight and review recommendations of the LD 1252 Work Group for viable alternatives to current public guardianship structure. Develop and offer orientation and training for anyone currently or planning to serve as guardian, and contract with an external organization to oversee public guardianship.

- **Futures Planning**: Hire an external organization to evaluate the person-centeredness and quality of the current person-centered planning process. Continue offering training from experts in personal planning models to providers, family members, and develop training in person-centered planning for individuals. Make technical assistance from person-centered planning experts available to planning teams.

- **Case Management**: Decrease the number of tasks and the paperwork required of CCMs and ISCs. Assess viability of case managers serving as PCP facilitators. Do not require case managers to evaluate quality of services-instead, use Quality Management Office staff for this task.

- **Work, and Finding Work**: Increase the number and quality of VR counselors working with ID/ASD population. Offer counselors training on developmental disabilities, autism, and personal planning. Create an advisory group of self-advocates, family, and community members for VR, and work with the Quality Management Office to develop and implement evaluations of VR experiences for individuals and family members.

- **Transportation**: Work with stakeholder groups to redesign system to ensure responsiveness to needs and characteristics of individuals using the service, enforce the Transportation Rules and contract components, with penalties for lack of compliance. Hire self-advocates to periodically use and assess quality of transportation services in each region, and develop and implement evaluation measures. Hire disability professionals to develop and implement training for EVERY driver, broker, and contractor-especially those working in the call centers.

- **Wait List Management**: Develop and maintain a means to stay in touch with, and regularly update contact information about, those on Priority 2 and 3 wait lists. Work with stakeholder groups to develop a more equitable system for collecting data about those on wait lists for use in the funding selection process. It is particularly important to avoid overlooking the needs of families that are caring for adult children with disabilities who do not file reportable events or otherwise use current OADS markers for determining immediacy of need for funding.

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 report to the Commissioner, the Office of the Governor, and the Joint Committee on Health and Human Services in partial fulfillment of our responsibilities as outlined in statute. In this report, we provide an overview of concerns 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 is informed by the Board's work on various collaborative committees and work groups during 2015-June 2016, as well as comments from the Public Feedback Forum Series[1] held in October and November. Again this year, we focused most of our attention on the Office of Aging and Disability Services (OADS), although Vocational Rehabilitation Services (VR) continues to be an area of concern identified by individuals, their family members, and their caseworkers.

This report includes outcomes from the Volunteer Correspondent Program, Public Feedback Forum Series 2015 Report, and a list of MDSOAB members and MDSOAB activities during the report period.

2015-2016 Final Report
Priorities and Recommendations

Communication
A recent Forum Series conducted by OADS for individuals and family members focused on ways to improve communication between the Department and those it serves. We find all these developments to be positive signs that OADS is aware of the communication issues experienced by those outside the Department, and is actively working to remedy them.

1. **Communication between OADS and those outside the agency is**
   - *difficult for individual service users to understand,*
   - *difficult for family members to access, especially on the OADS website, and*
   - *primarily one-way with stakeholders,*
   - *unresponsive to attempts to contact OADS administrative staff*
   - *inconsistent across offices*
   - *often too late to be of use.*
   - *It is often impossible to determine the right OADS staff member to contact, and key names and telephone numbers are not posted or shared.*

A. Issue: Individuals report having difficulty understanding communication from OADS.

Recommendations:
- Work with contractor experienced in evaluating and modifying text reading levels.
- Ensure that all information impacting the lives of individuals are available in more than one format (i.e. text, auditory, YouTube clips)

B. Issue: Individuals, family members, guardians, allies have difficulty accessing information, especially on the OADS website.
The MDSOAB has since learned that OADS does not have editing control over the layout of information on their web pages.

Recommendations:
- First, allow OADS- and other Departments- to direct the content and specifications for presentation when relevant
- Create web page for individuals with alternate formats for important information affecting their lives;
- Create a web page for family members, guardians, allies, with relevant information. Guardians helped sketch out the kind of information they'd like to see on a web site. This list is in the 2014 Public Feedback Forum Outcomes.
- Work with a contractor experienced in Universal Design in web formats to create these pages; require contractor to vet design, various versions with SUFU and parent groups throughout the design process.

C. Issue: Information disseminated by various offices at OADS often conflicts with that of other offices; information is shared too late to be useful; calls are not returned in a timely manner.

Recommendations:

- Use distance technology and the website as much as possible for transmission of information to ensure that everyone gets the same message at the same time.
- Dedicate a web page to weekly information updates for caseworkers and providers.
- Work with OADS Quality Management to identify barriers to timely return of telephone calls, and implement solutions.
- Post telephone names and telephone numbers of key people online so that others do not waste time trying to find the correct number and explaining the same issue multiple times while searching for someone with an answer.

MDSOAB Experience with Department Communication

Proposed rules are not shared prior to posting for public comment (which we understand is outside the control of OADS during this administration); the posting process itself was flawed for the proposed Behavior Regulations. The Department was responsive to MDSOAB's suggestion that they re-post the proposed Behavior Regulations, publicize the posting more widely, and allow everyone the full allotted time to formulate comments. The second public comment period for these regulations had many participants.

Systems change initiatives (i.e. proposed Section 21 Waiver redesign) were shared with stakeholders, but the communication about proposed changes was usually one-way, with the Department sharing updates but not seeking input to be used for meaningful change. Instead, steps in the development process were shared with those outside the Department after development was finalized and, in some cases, out for public comment. We understand that the comments offered by the public are guiding the revising of the Section 21 Waiver application and program redesign. We are waiting to see evidence of this.

After several months with little communication and no data received from OADS, the MDSOAB took steps to re-establish ongoing communication with the OADS Director and Program Manager. We met and agreed upon a process for ongoing communication and collaboration. Since then, the Board has reviewed and commented on the CMS transition plan for compliance with the new HCBS rules. The DS Program Manager attends Board meetings, and individuals from OADS with content expertise present on topics requested by the Board.

Department Services

Adult Protective Services and Crisis Services are offered directly by the Department, and respond to more serious rights violations or unsafe conditions or events affecting individuals receiving home and community-based services. APS investigates reportable events that involve serious rights violations and potential exploitation or abuse. Crisis Services responds to individuals experiencing serious episodes of challenging, unsafe behavior, and those in danger of losing their residential placement. Crisis Services offers a number of service options ranging from consultation by telephone to temporary out of home placement.

2. Adult Protective Services
APS investigations, when done in a timely manner and when results are shared, were viewed by most as helpful. Issues arise when

- *there is a lack of response to incidents where there is the potential for injury or exploitation,*
- *longer than 2 weeks is permitted to pass before an event is investigated,*
- *investigation reports are not shared, and*
- *calls and e-mails to APS investigators and supervisors are not returned.*

***Issue*:** Multiple days or weeks can pass before an event is acted upon, if it is acted upon at all.
Recommendation:

- Ensure that every non-routine event sent to APS is acknowledged by notifying the reporter of the investigator's intent to investigate (or not) and the timeline by which this will happen.

Issue: Written reports, regardless of the seriousness of the outcome, are no longer shared outside the Department.

Recommendations:

- Follow the directive in Chapter 12, 6.04 G. 3(c) "*The final report will be forwarded to the provider agency, the person or their guardian (except when the guardian is the subject of an investigation), the person's ISC, the Department's Regional Office, the Office of Advocacy and the Consumer Advisory Board, or its successor." In the event that there is an issue of confidentiality, a partially de-identified copy may be shared.*

***Issue*:** Attempts to contact APS outside of reportable events can be difficult.

MDSOAB experience with Adult Protective Services involves a volunteer correspondent about whom a provider made allegations. The coordinator could not determine if the allegation was reported to APS by the case manager (it was not), and could not get APS to return her calls or e-mails. She finally reported the allegation to APS herself. This situation impacted the individual, the volunteer correspondent, and the integrity of the Volunteer Correspondent Program. This could have been a safety issue. To date, the VCP coordinator has not received any information from APS on the matter.

Recommendations:

- Increase staffing so that investigators have time to respond to inquiries outside of reportable events forms.
- Designate an APS staff member (possibly a supervisor) to ensure that every query receives a prompt response.

Crisis Services
Crisis Services remains an area of concern not because of the quality of the service; rather, the office appears to be understaffed. Specifically:

- *It often takes a long time for staff to respond to a crisis request; providers report that they often call back or arrive after the crisis has been addressed in less desirable ways*
- *Most team leaders have little time to develop resources in the array of options that should be available to individuals and their support teams.*

- *The call-in process, which uses one number and one operator for both MH and ID, is confusing to many individuals and they are often directed to the wrong service by the telephone service.*

Issue: Crisis Services staff often cannot respond in a timely manner, and team leaders frequently need to cover direct support hours. The current staffing does not permit every bed to be used when needed, because often at least two staff are needed to support one person 24 hours per day.

Recommendation:
- Staff Crisis Services at the ratio of staff/people served recommended in Community Consent Decree, when Crisis Services was created.

Issue: Crisis teams have very little opportunity to teach provider staff about proactive approaches to behavior management. With adequate resources, Crisis staff could spend more time educating provider staff about positive supports, providing in-home support, and developing other proactive responses to challenging behavior.

Recommendations:
- Provide CS staff with technical assistance to learn how to teach specific techniques for supporting people with challenging behavior.
- Increase staffing so that staff has adequate time to build provider capacity for managing challenging behavior
- Re-orient Crisis Services toward providing trainings to provider staff, and toward providing ongoing in-home technical assistance to lessen the need for out-of-home placement.

3. Guardianship

Guardianship, especially public guardianship, remains an issue of particular concern:
- *numerous individuals would like to be emancipated from the guardianship relationship*
- *individuals and family members lack alternatives to guardianship*
- *family members want to participate in trainings relevant to guardianship*
- *the guardian role for public wards is represented by the individual's Individualized Service Coordinator (ISC), which those outside the Department recognize as a conflict of interest for the ISC, the Department, and is not in the best interest of these individuals.*

Issue: Maine currently lacks alternatives to guardianship.

Recommendations:
- Support the work of the Supported Decision Making Coalition with resources, facilities when appropriate, and ongoing participation in order to pilot SDM and create a model that works for Maine. Work with the Coalition to publicize and support a Supported Decision Making training initiative.
- Provide information about, and training for, those assuming guardianship over a person with ID/DD and ASD.
- Contract with an external agency to undertake a review of viable alternatives to Maine's current public guardianship structure. Set a goal for design and adoption of an alternative public guardianship structure in the upcoming Biennial Plan.

Issue: Individuals who lack a private guardian have their interests represented by staff of the Department of Health and Human Services, which is also the funding source for their services. In addition, those under public guardianship are not permitted to request a different case worker.

Recommendations:

- Refer to the recommendations of the LD 1252 Work Group Report to the HHS Committee of 2011 and examine the viability of each, or hire an external contractor to evaluate recommendations, update state information, and report back to Department.
- Give people under public guardianship the option to change case managers if desired.
- Require training about guardianship for ISCs currently representing the state guardianship role.
- Institute a plan to monitor public guardianship with an agency external to the Department to oversee relationships between public guardians and individuals whom they represent.

4. Futures Planning

Maine uses its own version of a personal planning process for each individual receiving services. This plan is intended to determine and follow each person's services and annual goals. The process, called a PCP, was revised and the new process began implementation approximately two years ago. Since that time, individuals report feeling that the meetings is more confusing and that input emphasizes staff more than the individual; families and direct support professionals report that the process no longer feels person-centered, and case managers, who are charged with coordinating the new process, report feeling overwhelmed with meetings and paperwork. Some system veterans believe they can no longer offer high quality services to their clients with all the tasks added to their work in recent years.

Issue: While a lot of effort and training went into the current PCP process, individuals, family members, and support team members find that it is less person-centered than ever. The final meeting has become a dry report-out rather than a brainstorming session.

Recommendations:

- Hire an external consultant with direct, demonstrated expertise in personal planning models to evaluate representative PCP documents for alignment with tenets of personal planning. An additional component might be to conduct subsequent interviews with several people whose PCP was under review to determine their perceptions of the process.
- Continue the work begun by the recent Community First Conference by offering subsequent conferences to guide support providers in understanding the underlying belief system on which personal planning relies.
- Offer technical assistance from experts in personal planning to provider planning teams.
- Develop and offer training about person centered planning to individuals who have plans.

5. Case Management

Again this year, individuals seem happy with their case managers and rely on them for a variety of reasons. Case workers themselves enjoy working with their clients, but find the amount of documentation and the added responsibilities related to the new PCP format overwhelming, and many believe they can no longer provide quality case management services.

- ***Issue:*** CCMs have too many responsibilities that increasingly pull them away from directly supporting their clients. CCMs should not be asked to take the place of person-centered planning facilitators, quality assurance professionals, AND sources from which all communication is expected to flow.

Recommendations:

- Improve avenues for disseminating updated information directly from the Department in a variety of formats.
- Evaluate viability of CCMS serving as PCP Facilitators vs. PCP facilitators working within provider agencies.
- CCMs do not have the breadth of familiarity with services across districts and providers to effectively evaluate quality of services. Develop, with the Quality Management Team, a viable plan for ongoing evaluation of service quality across the state.

6. Work, and Finding Work

Individuals continue to express the desire to work. They, their family members, and their case managers identify Vocational Rehabilitation as one of the biggest obstacles to employment. VR involvement was reported to rarely end in employment; in fact, some case managers report that VR talked their clients OUT of employment. Families and individuals report that some VR counselors do not listen to the individual's employment interests and instead suggest jobs in which they are not interested and, at worst, are perceived to be rude to and dismissive of individuals. One VR counselor was reported to insist that the individual being served leave his own meeting.

People report being required to meet with VR, then with either a Career Exploration or Employment Specialist, and then back to VR, then back to employment support. Some report having entered VR with a job, and being told that they could not keep that job because VR had not been involved in getting the job. We at the MDSOAB can only report what we are told by individuals, their family members, and case managers, and we are puzzled by this inefficient VR process. Whether or not the process outlined above is correct, the perception of those being served remains as reported.

Issue: There appear to be systemic problems with VR services that cannot be improved with a few recommendations, and the MDSOAB has not focused on this area in any depth as yet. We believe, however, that the following recommendations would be good activities with which to start.

Recommendations:

- Increase the number of VR counselors serving the ID/ASD population. We understand that individuals, once referred to VR services, often wait months before seeing a counselor. We also understand that counselors have caseloads that are far too large to allow quality service.
- Offer training for counselors on topics like disability etiquette, characteristics of autism, and person-centered planning (specifically- demonstrating how to move an employment statement from idea to action steps).
- Create an advisory body for VR that is comprised of strong self-advocates, family members, and community employers (i.e. Chamber of Commerce members) to offer suggestions for improving services.

- Establish a system, with the help of the Quality Management Office, for individuals to evaluate their VR experience on an ongoing basis, and use this data for develop quality improvement action plans.

7. Transportation

Transportation continues to be a barrier to employment, community participation, health care, and safety. Changing brokers did very little to address the underlying issues. The transportation regulations offer a structure that does not appear to be enforced. As one individual said at a forum, "If YOU knew them, you wouldn't want to ride with most of them, either!" Drivers show up early, late, on the wrong day, or not at all. Call center staff are often rude to individuals and family members. Many drivers are either unaware of or don't follow the specifications in the transportation contract; i.e. no smoking in vehicles. Individuals are expected to ride with a series of unfamiliar people, or in vehicles with characteristics that are counter to his or her disability-related accommodation needs.

Issue: Drivers arrive early, arrive late, and sometimes do not arrive at all. The current service agreement between brokers and OADS permits transportation providers to be up to ½ hour earlier or later than scheduled. Individuals are missing work, day program, and needed medical appointments as a result.

Recommendation:

- The primary goal of community-based service is to provide adults with ID/DD and ASD the same services and experiences. ***No person without a disability would be expected to tolerate a transportation service arrives and departs at the provider's convenience rather than the client's. Nor should individuals with disabilities***. The system needs to be redesigned so that individuals get the transportation that works best for him or her.

Issue: Some drivers smoke in the vehicle, drive in unsafe ways, and appear to have little to no training or orientation about acceptable ways to interact with people with disabilities. Some of the transport vehicles are inappropriate for the person traveling; others are just unsafe.

Recommendations:

- The model of transportation provision specified in the regulations requires a contract between the broker and contractor, training for drivers, and sets out standards for the vehicles to be used. These should be enforced.
- Establish sanctions for drivers who violate the standards. The sanction should also impact the transportation broker, as it is their responsibility to monitor quality of services they provide.
- Establish a fund to hire SUFU members in each transportation provider region to contract with service providers and evaluate their experiences. This will serve as an additional way to assess quality of services.

Issue: Individuals, family members, and providers alike report no response, or rude response, from brokers. There appears to be little to no quality assurance or accountability for brokers or contracted drivers. The state is paying for sub-standard service.

Recommendations:

- Involve the Quality Management Team immediately in designing a means to evaluate transportation brokers and contractors. Develop accountability with real consequences for sub-standard service.
- Hire external disability professionals to provide training to drivers, brokers, and contractor service personnel. Going forward, require this to be completed before the broker, contractor personnel, or drivers are permitted to offer transportation.
- Work with stakeholder groups (i.e. State Independent Living Council) to entirely redesign the current transportation provision system. Acknowledging that transportation is problematic is not enough- there must be a solution offered.

Issue: Individuals are expected to accept transportation under conditions that negatively impact their health or comfort. MaineCare appears to misunderstand the notion of "services approximating those used by people without disabilities," They appear not to recognize that individuals are receiving Medicaid waiver services BECAUSE he or she has disabilities that may affect his or her ability to ride comfortably (without undue anxiety as well as with physical comfort and safety) in a taxi or other mode of transportation. When accommodations are appropriate, they should be provided.

Recommendations:

- Respect and follow the accommodations requested by each individual. They should not be expected to endure discomfort, anxiety, or lack of safety during transportation.

8. Wait List Management

The MDSOAB appreciates the great effort the Department and the Legislature, per recommendation from the Joint Committee on Health and Human Services, have devoted to eliminating wait lists for those seeking Section 29 services and for those formerly on the Section 21 Priority 1 Wait list. We were encouraged to learn that OADS was developing a process for selecting the next individual to receive Section 21 funding and hope that this effort continues. Finally, we applaud OADS for their effort to contact every person who was on the Priority 2 Wait list for Section 21, and to collect the same information from each in order to select the people to be offered the recently funded 200 additional slots. Each of these things demonstrates the Department's commitment to chipping away at the wait list in a manner that is fair to all.

Issue: The efforts mentioned above do not at present extend to contact or collection of information from individuals and families on the Priority 3 wait list. In addition, the Office discovered that contact information for many people on the Priority 2 list was outdated. There are no additional efforts to find these people.

Recommendations:

- Improve ongoing connection, communication, accuracy of data, with those on lists, especially Priority 3. It has been demonstrated many times and in many arenas that the information in EIS is often outdated and inaccurate. Develop a way outside of EIS to stay in contact with individuals and their families.

Issue: It appears that the current selection process still relies on reportable events as part of the selection process. This often excludes families who do not have ongoing contact with case managers, or who do not file a reportable event form for every issue that arises; in addition, many families have learned to accommodate challenging behavior in the home that would arise often in any other setting.

Recommendation:

- Develop, with input from a parent group, and use a selection process that is as equitable as possible and takes into consideration a variety of factors, including impact on family, and erosion of individual's skills and health while waiting for services- factors not measured by EIS or Reportable Events

Appendix A

MDSOAB Activities

A. Participation on Regional Three-Person Committees

MDSOAB members and director served on Three Person Committee reviews of Severely Intrusive Behavior Plans and Safety Device applications.
Safety Devices are approved annually.
There are 443 approved safety device applications statewide.

New Severely Intrusive Behavior Plans, or SIPs, are reviewed after the first month of implementation, two months after the first review, and then every three months. Once in place, the SIP is reviewed every three months until it is no longer needed. They are intended to be short-term responses to unsafe behavior.

There were 115 active Severely Intrusive Behavior Plans in place as of January 2016. We estimate that MDSOAB members and staff participated in at least 60 regional Three Person Committee meetings and reviewed individual plans nearly 1400 times during the year.

B. Participation on Statewide Three Person Committee Team

Every member of a Three Person Committee participates in bimonthly 3PC Statewide Team meetings. These meetings are used to discuss interpretation of various parts of the behavioral regulations with the goal of coming to a consensus about interpretation, or the points to be reviewed when interpreting; discussing process and developing ways to ensure that each team is following roughly the same process across the state, and any other questions or concerns relating to plan reviews that arise.

During the spring of 2016 the new behavioral regulations went into effect. We are currently educating ourselves, and each other, about new requirements, standards, and interpretation of the new regulations. Again, we seek to ensure consistency in process and interpretation across regions.

C. Public Comment

The MDSOAB offered both written and oral comment on a number of proposed changes in programs and proposed new rules and laws, including

- New Behavior Management regulations: November 2015
- LD 475: Spring of 2015 and March 2016
- Proposed changes to Section 21: January 2016
- Hearing re Supports Intensity Scale: March 7, 2016

D, Collaboration

The MDSOAB Director participated in the ***Employment First Maine Coalition*** and on the EFM Transition Work Group throughout the report period.

MDSOAB coordinated planning, implementation, and data collection for the ***Public Feedback Forum 2015 Series***. The series is developed and undertaken with collaboration from Maine DDC, SUFU, Maine Parent Federation, U of Maine Center for Community Inclusion and Disability Studies, and the Volunteer Correspondent Program of Maine. MDSOAB takes responsibility for analyzing and organizing forum results into topic areas, and for creating the Forum Outcomes Report. See Appendix C for Public Feedback Forum 2015 Executive Summary.

Members of the MDSOAB participated in the ***HCBS Transition Stakeholder Group***, and the ***ICF-IDD Stakeholder Group***.

Appendix B

Board Membership

Current appointed members as of June 2016: Irene Mailhot, Rory Robb, Jennifer Putnam, Cullen Ryan, J. Richardson Collins, and Ann-Marie Mayberry

Current nominated members: Richard Estabrook, Kim Humphrey

Current nomination in progress: Alan Kurtz

Representatives from Maine DDC and DRM- Each organization has seat on the MDSOAB as specified in statute.

Inactive Member Status: Tyler Ingalls

Resigned from Board: Bonnie-Jean Brooks, Steve Richard.

Dropped from Board due to lack of attendance: Linda Elliott.

The MDSOAB continued to experience a lack of response from the Office of the Governor from January to December of 2015. In January, several nominated members received appointments from the Governor.

Unfortunately, two members remain in nomination status although they were vetted by the Board, attend and participate in meetings, and completed and submitted all the required documentation for approval. The comment back from the Office of the Governor indicated the governor's belief that board membership is not "balanced" in terms of political party affiliation, so two members were not immediately appointed.

The MDSOAB continues to exist as a non-partisan advisory board. Political party affiliation is not asked about at any point in our nomination process; nor is it remotely relevant to our responsibilities as outlined in statute. We seek individuals with great depth of knowledge about services for adults with ID and autism and a strong willingness to work toward ensuring that these services become or remain of high quality and great availability. Our members are all volunteers and do not experience any political benefit from their participation.

We find it unfortunate that perceived political affiliation has been permitted to negatively affect our organization, which is neither influenced by nor interested in the activities of any political party.

Appendix C:

Public Feedback Forum Series 2015

Executive Summary

Entire report available upon request to
mainedsoab@gmail.com
622-5370

Public Feedback Forum Series 2015
Executive Summary

The Public Feedback Forum Series gathered input about Maine services for adults with intellectual disabilities or autism from September to December 2015. Information was gathered from **151 individuals** who receive services from OADS (or who are on the waiting list), **67 family members** and allies, and **149** DSPs, CCMs, or administrator/other **providers**.

Public Feedback Forum 2015 collaborators include Maine Developmental Services Oversight & Advisory Board (MDSOAB), Volunteer Correspondent Program of Maine (VCP Maine), Maine Parent Federation (MPF), U Maine Center for Community Inclusion and Disability Studies (CCIDS), Speaking Up for Us (SUFU), and Maine Developmental Disabilities Council (Maine DDC)

Forums were held in Houlton, Biddeford, Norway, and Brunswick. Online surveys were developed for individuals who use OADS services[2], family members/guardians/allies, and community service providers. People who wanted assistance completing a survey called the Maine Parent Federation's toll-free number or requested assistance at forum events and the SUFU Conference.

Information was sorted into topic areas and analyzed for common themes. This report is an overview of the forum series outcomes. Section 1 features services provided by OADS, including communication with OADS, Adult Protective Services, Crisis Services, and Guardianship (both public and private). Section 2 outlines Case Management, and Section 3 presents Futures Planning: the PCP, the SIS, and Transition. Section 4 outlines Working and Finding Work; and Section 5 is about Transportation. Section 6 contains Conclusions and Recommendations.

1. Communication with Department

- ***Individuals*** report difficulty understanding information from OADS.

- ***Family members and allies*** find the DHHS website difficult to navigate. When asked about their satisfaction with information from OADS about changes in their family member's services, they were (in descending order) neutral, satisfied/very satisfied, or dissatisfied/very dissatisfied. Families moving to Maine from other states had a difficult time getting any information from DHHS about services, and one reported that DHHS lost all the documentation sent about her son.

- A majority of ***Providers*** report difficulty communicating with OADS. The top three barriers identified were (in descending order) "messages are not shared uniformly across interested parties"(nearly 60%), "contact person does not return call or e-mail" (54%), and "official response or directive conflicts with each other or with prior directive" (47.1%).

Department Services

"Department Services" are defined for the purpose of this document as those provided by the Department directly to individuals. We focus on Adult Protective Services (APS), Crisis Services, and Guardianship in this section; case management is reported in a subsequent section.

[2] I Available upon request to mainedsoab@gmail.com, or by calling 622-5370.

A. Adult Protective Services (APS)
There are two types of APS: one focuses on people who are elderly, and the other, which is the topic of this report, focuses on adults with intellectual/developmental disabilities and ASD.

Neither ***individuals*** who use OADS services nor their ***family members and allies*** had comments about APS.

More providers agreed than disagreed that APS, when they respond at all, responds to issues of concern in a timely manner, and that APS investigations are helpful to them in their work (case managers, direct support professionals, and administrators were included in this survey). The following issues were identified:

- ***APS is not helpful*** (13 comments) Inconsistencies in procedures across districts, lack of effective intervention, and less smooth functioning than in previous years were all identified.
- ***Decision to ignore statute and no longer share written reports is unhelpful/dangerous*** (12 comments)
- ***Overburdened system*** (7 comments) Specifically, a need for more investigators was noted.
- ***Lack of collaboration across districts*** (4 comments)

B. Crisis Services

As noted in the 2014 Public Feedback Forum Report, Crisis Services continues to be under-resourced and under-staffed. As one commenter wrote, ***"Crisis Services is in crisis!"*** (survey comment). Of the 6 discrete types of crisis responses named in statute, the team's ability to offer all 6 types differs across regions in the state.

Of the people commenting on Crisis Services, a slight majority reported difficulty getting Crisis team assistance in a timely manner. A majority believed the current Crisis Service capacity does not meet the needs of the system. Given that Crisis Services has never been staffed at the level identified in the 1995 Community Consent Decree, yet the number of individuals with disabilities living in the community has increased significantly over the past 21 years, this is not surprising.

The 29 comments about Crisis Services fell into tw general categories:

- ***Not enough resources (crisis beds and staff)*** (N=13)
- ***Communication is poor (long response times, and issues with call-in number)*** (N=12)

The remaining commenters noted a lack of consistency across districts, and suggested that both crisis workers and case managers be trained to work with people with dual diagnoses (mental illness and intellectual disability).

C. Guardianship

A majority of individuals attending forum events and responding to survey questions have either private or public guardians. Of those who have a guardian, half report that they would like to "be my own guardian" some day. Most did not know about ***Supported Decision Making*** as an

option, and nearly all had an interest in learning more. Without a guardian, individuals believed they would have control of their own finances, be able to go places without staff supervision, be able to assume responsibility for their own lives, and, in the words of one person, ***… to have my own future.***

Family members noted that there were no systemic alternatives (other than full guardianship) offered when their family member reached the age of majority. They wanted information and training about alternatives to guardianship like Supported Decision Making***.***

Providers discussed guardians who are uninvolved in the lives of their wards. They would like trainings about guardianship. Providers and family members were concerned about the conflict of interest arising from the Department serving as guardian for wards of the state. In theory, the state is the guardian. In practice, the case manager represents the state. The individual has little recourse if he or she disagrees with the case manager's decisions, and cannot change case managers like those with private or no guardians can do. The funding agency has ultimate decision-making power in determining the individual's services.

2. Case Management

Individuals continue to have positive regard for their case managers. Case managers have become the primary, if not only, source for information about current and available services, changes, and other systemic topics.

Case managers report feeling overwhelmed by increased responsibilities added to case management. Some believe they no longer offer quality case management. The added pre-meeting meetings and complicated documentation of the current PCP process results in more running around, and less actual planning, than with the previous protocol. Updating EIS and other documentation, which cannot be accomplished while on the road over an unsecured connection, results in either taking work home every night or neglecting documentation entirely.

3. Future Planning

A. Maine's Person-Centered Planning

Most individuals attend at least part of their PCP meetings. They, family members, and providers think the current PCP process is less person-centered than before and stifles the team's creative process.

B. Supports Intensity Scale

Again, all three populations reported dissatisfaction with, and objection to, the current SIS Interview/Rate Setting Package model. There was inconsistency across interviewers. While the SIS yields useful information, many guardians and providers report that the associated rate package is much less than the individual currently receives. Overall, they believe that implementation of this model will result in less individualization of services and less meaningful community inclusion than currently exists.

C. Transition

Families moving to Maine from other states report being unable to get answers or assistance from DHHS personnel. One mother reported sending all her son's records, which were lost by OADS. Another family reported no success in identifying someone to address their questions and concerns.

4. Working and Finding Work

Individuals continue to prefer work over other activities. Despite this, they report difficulty getting help to find or keep a job, other than from family members and case managers.

A. Vocational Rehabilitation

Vocational Rehabilitation, or Voc Rehab**,** did not yield a single positive comment from individuals, guardians, or providers at any level. The service was identified as very slow, unresponsive to the desires of the individual, lacking in appropriate aspirations for individuals, and difficult to work with. Cases are often closed before the individual has secured employment.

B. Employment Specialists

Employment Specialists help the individual learn job tasks, and support them onsite. There were questions about the level and kinds of training these specialists receive. Case managers have difficulty getting employment specialists to respond to online "vendor calls" for services.

C. Career Planning

There appear to be too few resources for this new service. Some people had questions about how Career Planners fit into the employment support system.

5. Transportation

Like Voc Rehab, Transportation was a topic everyone seemed to agree upon: it is terrible. **Individuals** report drivers who arrive early, late, or not at all; or who drive too fast, smoke, swear, yell at them, and have questionable hygiene, or who "scare the bejeezus out of me!" They report being stuffed into small cars without adequate room, or missing appointments because no accessible vehicle was available the day of the appointment although it was requested. Some people have lost jobs or day program hours because of consistently inconsistent transportation.

Guardians and family members report rude brokers or contractors, lack of consistent or safe drivers, and an unresponsive complaint process. They identified an unequal process: individuals cannot be late or miss a ride more than twice or they are denied services; but there appear to be no consequences (accountability) for transportation brokers or contractors.

Case managers and providers worry about individuals losing medical specialists, being left alone up to an hour early at a facility or picked up more than an hour late, delivered to the wrong location, driving with people who are smoking and talking on cell phones (both prohibited), and engaging in all kinds of unsafe behavior. Many providers have re-assumed transporting their clients out of fear for their safety. Although the transportation regulations identify requirements for brokers and transportation contractors, there appears to be little to no attention given to them.

6. Conclusions and Recommendations

There are key issues and recommendations identified for each area identified above.