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Maine Developmental Services
Oversight & Advisory Board

# Annual Report

## July 2016 to June 2018

**MDSOAB Maine Developmental Services**
**Oversight & Advisory Board**
**Annual Report**
**July 2016 - June 2018**

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# I. MDSOAB Annual Report: Executive Summary

We respectfully submit this annual report to the Joint Committee on Health and Human Services, DHHS, and to the Office of the Governor. This report details the oversight activities of the MDSOAB from June 2016 to June 2018, and includes recommendations for action on each of our 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, and our own observations, especially in the Board's participation on the Regional and Statewide Review Teams that review all of the most restrictive Behavior Management Plans submitted by providers throughout the state.

The recommendations are also based on comments from the 2017 Annual Public Feedback Forum, which was coordinated by the MDSOAB in collaboration with the Maine Coalition for Housing and Quality Services, which includes members of 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), and the Maine Parent Federation (MPF) among a total of fourteen district councils and advocacy groups.

Comments were provided by clients and self-advocates, family members, guardians, volunteer correspondents, and service providers (including administrators, case managers, and direct support professionals). An Executive Summary and a complete account of the comments are included as Appendices to this report.

A 2018 Public Forum was also held at the June and July meetings of the Coalition. Many of the concerns voiced in 2016 and 2017 were heard again in 2018. Links to the minutes of the June and July meetings can be found at the Coalition's website at: http://www.maineparentcoalition.org/agendasminutes.html A transcript of the minutes will also be included in the next Annual Report along with an analysis of the department's responses to the concerns voiced at the Forum.

The OAB has consistently communicated to OADS and to DHHS that we see ourselves as an ally in serving the needs of those with intellectual disabilities and autism. We sincerely hope that they regard the Board as an asset in identifying problems in the delivery of services and in providing assistance in developing solutions with input from stakeholder groups.

## *Recommendations include:*

- **Crisis Services and Adult Protective Services:** Increase staffing of both services and improve responsiveness to requests, questions or concerns from the field. APS should reduce the time between notification of an incident of exploitation, abuse or neglect and the start of an investigation, and should resume sharing written reports with MDSOAB as directed by statute. Crisis Services, with adequate staffing, should increase use of proactive strategies and develop trainings for providers, which should help reduce the number of crisis bed placements. Create an independent Mortality Review panel similar to the one proposed in the last Legislature.

- **Wait List Management**: Develop and maintain a means to stay in communication with -- and maintain current contact information for -- those on Priority 2 and 3 wait lists for MaineCare Section 21 waiver services. Work with stakeholder groups including MDSOAB to develop an equitable system for prioritizing and selecting funding and placement for Priority 2 and Priority 3 individuals. It is important not to overlook families who care for adult children with disabilities and who do not file reportable events or otherwise use current OADS markers for determining priority for placement.

- **Public Guardianship:** Work with stakeholders to develop alternatives to full guardianship. The replacement of the current Probate statutes which will take effect in July, 2019 will mandate viable alternatives to public guardianship. Develop orientation material and offer training for anyone currently serving as a guardian or planning to become a guardian. Contract with an external organization to oversee public guardianship.

- **Futures Planning**: Continue to offer training from experts in personal planning models to providers and family members and develop training in person-centered planning for individuals with intellectual disabilities and autism. Make technical assistance from person-centered planning experts available to planning teams.

- **Case Management**: Decrease the number and variety of tasks and the paperwork required of Community Case Managers and Independent Service Coordinators. Do not require case managers to evaluate quality of services - instead, use Quality Management Office staff for this task. Assess the role of case managers serving as PCP facilitators.

- **Section 29 Services**: Increase the number and quality of Vocational Rehabilitation counselors working with IDD/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 of individuals using the service. Enforce the Transportation Rules and contract components, with penalties for lack of compliance. Hire disability professionals to develop and implement training for EVERY driver, broker, and contractor-especially those working in the call centers.

- **Communication with OADS**: Encourage the Office of Aging and Disability Services (OADS) to work with existing stakeholder groups including MDSOAB to share information about the department’s short and long-term plans, activities and initiatives. Ensure that the OADS web page meets all accessibility requirements for contents and layout. Ensure that information 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.

## II. MDSOAB Annual Report: Introduction

The Maine Developmental Services Oversight and Advisory Board (MDSOAB) is charged with oversight of all Maine services and supports for adults with intellectual and developmental disabilities [“mental retardation” in the original statute] and autism. MDSOAB submits this report to the Joint Committee on Health and Human Services, the Office of the Governor, the Commissioner of the Department of Health and Human Services in partial fulfillment of the responsibilities as outlined in statute.  In this report, we provide an overview of concerns and recommendations to address systemic issues 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 with provisions for a part-time Volunteer Correspondent Program Coordinator.

This report is informed by the Board's work on various collaborative committees and work groups beginning from the date of the last report (June 2016), as well as comments from the Public Feedback Forum described in the Executive Summary.  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, and the processes of the Office of Child and Family Services (OCFS) and the Office for Family Independence (OFI, which determines eligibility) were often mentioned as well.

This report covers two calendar years, from July, 2016 to June, 2018 (with a few updates from July).  The Board had three Executive Directors over that time span, including a period of several months when the position was vacant. I assumed the role in April, 2018 and began to work on the Annual Report as soon as I began to have a feel for my new duties.  The next Annual Report will cover July, 2018 through June, 2019.

Mark Kemmerle
Executive Director, MDSOAB

# III. MDSOAB Annual Report: Priorities and Recommendations

## Departmental Services

Per statute, Adult Protective Services and Crisis Services are offered directly by the Department (not through providers) 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 allegations of abuse, neglect or exploitation. Crisis Services responds to individuals experiencing serious episodes of challenging, unsafe behavior. Crisis Services offers a number of service options ranging from consultation by telephone to temporary out of home placement.

### 1. Crisis Services

***Issue: Lack of available crisis beds***. The MDSOAB has become aware over the past year of numerous situations in which a person finds him/herself in a crisis placement for weeks or months while a new placement is being sought. A person may be placed in a crisis bed for a number of reasons, but the placement is most often accompanied by a discharge from the provider. Rarely does a person return from a crisis bed to their former placement. Essentially, when a person is placed in a crisis bed, it means that the provider has exhausted its ability to provide for the client and is removing itself from the equation.

The Community Consent Decree required 24 crisis beds in the system of care. Of those 24, 12 were to be state-run and 12 were to be privately run. In December 2016 the provider who staffed the privately-run beds withdrew from its contract and announced that it was discontinuing the service. Those beds were lost to the system of care and they have not been replaced or replicated. The state currently provides four two-bed crisis homes and has contracts for six additional beds for Emergency Transitional Housing.

When the Community Consent Decree was negotiated in 1994 the system of care served approximately 4500 to 5000 persons. Now the system serves approximately 5500 to 6000 people. The right to crisis services is guaranteed by state law 34-B M.R.S. 5206 which states (among other provisions):

> The department shall maintain the capacity to intervene in personal crises that could lead to the loss of the home, program, or employment of a person with an intellectual disability or autism.
>
> The department shall maintain an adequate capacity to provide out-of-home safety and support by trained staff with appropriate backup resources for a person with intellectual disability or autism experiencing a crisis that cannot be safely managed at the person's residence.
>
> The department shall maintain information regarding the use of crisis and respite services sufficient to plan and budget for adequate crisis and respite services. The information must include an assessment of the needs, both met and unmet, for crisis and respite services.
>
> The department shall provide information regarding the availability of services.

The MDSOAB concludes from all information available to it that the department is not providing crisis or respite services in compliance with statute. It is difficult to get accurate statistics about the number of clients who are being temporarily housed in hospital emergency rooms for lack of a crisis bed placement. It is also difficult to get statistics on the average length of stay in a crisis placement. The anecdotal reports of lengthy stays in crisis beds indicate that the system is not adequately providing care for its most challenging clients.

***Recommendation:***

- Reinstitute a robust respite care program. Respite beds could be used for crisis beds in an emergency. Respite care would reduce stress on clients and families and could reduce the incidence of failed placements and crisis referrals.

***Issue:*** Crisis Services staff often cannot respond in a timely manner, and team leaders frequently are called upon 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***:

- Return staffing for Crisis Services to 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 Crisis Services 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.

## 2. Wait List Management

***From the 2016 MDSOAB Annual Report:***

“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:*** OADS continues to make efforts to chip away at the waiting list. In May of 2018, they reported to MDSOAB that they had extended 113 offers of support in the first four months of the calendar year. However, they also acknowledged that there were still over 1,700 people on the waiting list, over 400 classified as Priority 2 (at risk, though not at immediate risk, of Adult Protective Services intervention).

***Recommendation:***

- OADS is understandably proud of having no Priority 1 individuals on the waiting list, but for the last two years has not been able to make any inroads into the total number of individuals waiting for services. It's commendable that people are moving off the waiting list and being offered support, but the goal should be at least a 90% reduction in the list and an aggressive target for setting a maximum time spent awaiting services, once approved.

  **UPDATE**: The Legislature recently (July, 2018) allocated funds to move 300 people from the waiting list into Section 21 group homes. However, due to difficulties in recruiting and training direct care workers, the state's providers will likely not be able to act quickly to absorb even this number of new consumers. The Legislature is also to be commended for passing unanimously a bill that preserved and increased salaries and reimbursement rates for direct care workers, and for unanimously overriding the Governor's veto of that bill.

***Issue:*** Inadequate compensation for direct care workers. The OAB believes that there is a direct correlation between the low rates of compensation for direct care staff and the size of the Section 21 waitlist and the length of time that people have to wait in the "queue" for Section 29 services. The OAB notes that DHHS has made Section 21 service available to all those who are in immediate jeopardy of intervention by Adult Protective Services [the definition of Priority 1 classification.] But it is nonetheless unacceptable that the persons in the Priority 2 waitlist group are not yet receiving Section 21 services. By definition these are persons whose primary caregivers are over 60 years of age and who are having difficulty providing for their loved one at home; or the person with intellectual disability or autism is living in unsafe or unhealthy circumstances. (See 10-144 Code of Maine Regulations Section 21.03(B)(1) and (2))

The fact that the degree of jeopardy to the person has not yet risen to the level of immediate need of adult protective services does not excuse the state from meeting its responsibilities to these persons. The condition of the individuals on the Priority 2 Section 21 waitlist violates the statutory principles of service delivery articulated in 34-B M.R.S. Section 5610.

State law requires the DHHS Commissioner to provide funding to retain qualified direct-care workers employed by community services agencies serving Maine's citizens with intellectual disabilities or autism. (See 34-B M.R.S. Section 1208(7)). In addition, the Department is required to do an annual review of MaineCare fee schedules. In doing that review, the Department must consult with individual providers and their representative associations in order to consider, among other factors, the cost of providing specific services and the effect of inflation or other economic factors on the adequacy of the existing fee schedules. This annual review of fee schedules must be part of the Department's annual Medicaid report to the legislature. (See 22 M.R.S. Sections 3173 and 3174-B.) The last time Maine did a review that met these statutory requirements was in 2007, and that review was based on data gathered in 2005 and 2006.

> **UPDATE:** In the extended session of July, 2018, the Legislature unanimously passed the bill that preserved and increased salaries and reimbursement rates for direct care workers, and unanimously over-rode the Governor's veto of that bill.

Many providers increased pay to their direct care professionals based upon the one-year increase in reimbursement rates approved by the Legislature in 2017. The MDSOAB believes that there would have been a significant number of residential settings where people receive Section 21 services that would have been forced to close if the reimbursement rates had reverted to those paid prior to July 1, 2017. The lowered rates of reimbursement for direct care staff would have affected day programs and work and vocational support settings as well. If that had happened, Maine would have broken the promise it made to its citizens when the Pineland Center was closed, a promise to care adequately *in a community-based setting* for those with intellectual disability or autism.

**Recommendation:**

- Even with the July, 2018 wage increases for direct care workers, the relatively low wage scale for direct service providers makes it difficult to recruit, train, and retain the staff needed to support the system. It should be noted that although the state has allocated financial resources to qualify for the two-thirds federal match for Section 21 and 29 services, the provider community will still have difficulty hiring and training the staff to provide the care for persons eligible for Section 21 and 29 services. The state must assure that pay rates remain adequate to attract, train, and maintain a healthy, skilled labor force.

***Issue***: The current process to identify Priority 1 and Priority 2 individuals still relies on reportable events and Adult Protective Services reports 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 or ameliorate challenging behaviors in the home that would arise often in any other setting, thus understating the individual's need for support and services. .

***Recommendation***:

- Improve ongoing connection, communication, accuracy of data, with those on waiting lists, especially those classified as Priority 3. It has been demonstrated many times that the information in EIS (the State's software used to track services to clients) is often outdated and inaccurate. Develop a way outside of EIS to stay in contact with individuals and their families.

- Develop a selection process, with input from a parent group and MDSOAB, that is equitable and takes into consideration a variety of factors, including impact on family and erosion of an individual's skills and health while waiting for services -- factors that are not measured by EIS or captured as Reportable Events. It is important to move Priority 2 and 3 individuals off the waiting lists. Their lives can be changed and enhanced without incurring all the costs associated with meeting the needs of Priority 1 individuals.

### 3. Adult Protective Services

APS investigations are helpful when carried out in a timely manner and when results are shared, not only with the person who filed the report, but with the MDSOAB as well. However, when more than two weeks passes before an incident is investigated, or when results of the investigations are not shared, or when calls to APS investigators and supervisors are not returned, the system is not working and the risk of harm to individuals increases.

Input from the MDSOAB annual public forums consistently cited a lack of information about actions taken after reports were filed with Adult Protective Services. It was difficult or impossible to learn whether a reported incident had been investigated, whether the report had been substantiated, or whether any action had been taken. Through the rule-making process, the Department emended section 10-149, Chapter 1 and 5 on Adult Protective Services in May, 2018. All reports to Adult Protective Services are made directly to APS intake desk and are not entered into EIS as previously. The new process means that caseworkers and providers are completely excluded from the process once the initial report has been filed. In effect, the Department took one of the most frequently noted shortcomings of the APS system and made it worse – made it even more difficult to learn the disposition of an APS report. As a result, with no statistics provided and with no information shared, it is impossible to determine whether Adult Protective Services is in fact protecting adults with intellectual disabilities and autism from abuse, neglect or exploitation.at all.

***Issue*****:** Excessive time elapses before an event is investigated or acted upon, or no report is made of an event having been investigated 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".* Reports must be shared with the MDSOAB.

***Issue*****:** APS has not been responsive to follow-up inquiries outside the Reportable Events system. With new reporting process, reports will be made directly to APS Hotline and will not be entered into the EIS system. Any follow-up at all could be problematic and accountability is lost. .

***Recommendations:***

- Increase staffing so that investigators have time to respond to inquiries beyond responding to reportable events forms.
- Designate an APS staff member -- possibly a supervisor -- to ensure that every inquiry receives a prompt response.

***Issue*****:** The Office of the Inspector General found that the review and investigation of deaths of individuals under the care and supervision of OADS was inadequate. The Legislature passed a bill (LD 1676) establishing a Mortality Review process. The bill was vetoed by the Governor and the veto was upheld.

***Recommendation:***

- Reintroduce a bill to create a broad-based, independent Mortality Review panel similar to the one proposed in the last Legislature.

## 4. Public Guardianship

### 2018 Statement of issues for Guardianship/Probate:

A replacement of the Probate Code was adopted by the Legislature and will become effective July 1, 2019. The new Probate Code clarifies the existing laws around guardianship, incapacity, and how to support individuals with disabilities so that they retain as much autonomy as their capacity allows. For example, right now, a person with disabilities lacks capacity if they cannot "make or communicate responsible decisions." The new law seeks to ensure the person truly cannot make the decision even with support and all least restrictive alternatives. Under the new code, a person with disabilities lacks capacity if they are "unable to receive and evaluate information or make or communicate decisions, even with appropriate supportive services, technological assistance or supported decision making."

In simpler language, the new Probate Code tries to make sure people under guardianship have access to the support they need before, after, and during guardianship. It adds checks to make sure the person has the support they need before determining whether a full guardianship is required. It also changes the role of the guardian from a passive point-in-time decision-maker to an active facilitator whose goal is to help the person with disabilities be as independent as possible.

### *Impact of the new rules:*

Guardians who provide active and engaged support that allows the person for whom they are the guardian to be as independent as possible will be relatively unaffected by the change in the law. On the other hand, guardians who primarily sign papers or provide permissions and rarely engage with the person for whom they are the guardian may be more affected by the new statutes.

### *Issues to be addressed under the new Probate Code:*

In some cases, guardians may be appointed during a time of temporary crisis which may result from lack of access to proper support services (lack of assistive technology for communication while on a waiting list, for example). A permanent guardian or full guardianship may not be necessary if proper supports for decision making are provided. The new Probate statutes will help identify unmet needs to assure that full guardianship is the least restrictive option.

Public guardianship remains an issue. Individuals without a private guardian have their interests represented by the Department of Health and Human Services, which is also the funding source for their services. The Department reduced the conflicts inherent in public guardianship by eliminating many state case managers. However, in such cases where a state employee is the legal guardian, he or she is still both the person's decision-maker and the exclusive source of healthcare and services (i.e. community integration, work support, home support, etc.) which remains a major conflict of interest.

Numerous other issues also remain to be addressed. Some individuals would like to be emancipated from the guardianship relationship; others lack alternatives to guardianship. Family members desire training relevant to the roles and responsibilities of guardianship.

***Recommendations:***

- Support Supported Decision-Making with resources and facilities. Work to create a pilot SDM program and create a model that works for Maine. Publicize and support a Supported Decision-Making training initiative.
- Provide information about, and training for, those assuming guardianship over a person with IDD or Autism Spectrum Disorder.
- Contract with an external agency to undertake a review of viable alternatives to Maine's current public guardianship structure.
- Provide training about guardianship under the new Probate Code for DHHS staff who currently serve as public guardians.
- Hire an agency external to the Department to monitor public guardianship and oversee relationships between public guardians and individuals whom they represent.

### 5. Case Management

Individuals and their families seem generally happy with their case managers and rely on them for a variety of services. Caseworkers themselves enjoy working with their clients, but report that the amount of documentation and the added responsibilities related to the new PCP format are overwhelming, and many are concerned that they can no longer provide quality case management services.

***Issue:*** Community Case Managers 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 to continue to be the source from which all communication from the department 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. Person Centered Planning/ Futures Planning

Maine uses its own version of a personal planning process for each individual receiving services. This plan describes each person’s annual goals and outlines the services needed to help the individual attain those goals. The process, called a Person-Centered Plan (PCP) was revised in 2014. The MDSOAB’s 2016 Report noted that individual and their families felt that the planning meetings were confusing and that more input was provided by the staff than by the individual. Families and direct support professionals have remarked that the process no longer feels person-centered. Case managers, who are charged with coordinating the process, report feeling overwhelmed with meetings and paperwork and worry that they can no longer provide high quality service to their clients with all the tasks added to their workload in recent years. This trend seems to have continued through the first half of 2018.

***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 adherence to the principles of personal planning.
- Interview clients to determine their perceptions of the PCP process.
- Offer conferences and workshops in Person-Centered Planning for the benefit of community support providers.
- Offer technical assistance on an as-needed basis from experts in personal planning to provider planning teams.
- Develop and offer training about person centered planning to individuals who have plans and their families and guardians.

### 7. Section 29 Services

Individuals, especially those receiving Section 29 services, continue to express the desire to work. They, their family members, and their case managers identify lack of proper support from Vocational Rehabilitation as one of the biggest obstacles to employment. VR involvement seems rarely to end in employment; and some case managers report that VR seems to have talked their clients out of an interest in pursuing employment. Some VR counselors seem not listen to the individual's employment interests and instead suggest jobs – less challenging, unrelated, and even demeaning -- in which the clients are not interested.

The VR process seems cumbersome, often entailing a meeting with VR, then with an Employment Specialist, then back to the VR counselor, then back to employment support. Some report having approached VR already having found a job or a potential employer, and being told that they could not keep that job because VR had not been involved in securing it.

The OAB in this case can only report what we are told by individuals, their family members, and their case managers, but from anecdotal evidence, the VR process seems inefficient. Whether the stories related above are typical or representative, it’s difficult to say, but there seems to be a fairly widespread perception that the process can be both frustrating and intimidating.

Delay in providing Section 29 services is also an issue. The "queue", or waiting period, for Section 29 services is approximately six months as of this writing. This too violates the principles articulated in 5610, particularly 5610(1)(C). "Real work for real pay in integrated settings in the community" is supposed to be the "cornerstone for all vocational and employment services". The delay in the provision of vocational and employment services under Section 29 is an indicator of how far removed the system of care is from providing real work for real pay in integrated community settings. In addition, families need Section 29 in-home or community supports in order to stay employed themselves; they need the Shared Living service provided by Section 29 in order to either be compensated while not able to work themselves or in order to ensure adequate for their loved one in another home.

***Issue:*** There appear to be systemic problems with VR services that cannot be improved with a few recommendations. We offer following recommendations as a starting point. [A similar list was offered in the 2016 Report.]

***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.

## 8. Transportation

Individuals being served report drivers who arrive early, late, or not at all; or who drive too fast, smoke, swear, yell at them, and have questionable hygiene. 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. Clients have been delivered to the wrong location. Some people have lost jobs or day program hours because of 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 for missing appointments or for tardiness.

Case managers and providers worry about individuals losing medical specialists, being left alone at their destination up to and before their scheduled appointment, or picked up more than an hour late. Many providers have re-assumed transporting their clients out of fear for their safety.

Transportation continues to be a barrier to employment, community participation, health care, and safety.

**Issue:** MaineCare funds can only provide transportation to MaineCare services (primarily medical appointments). A monumental and systemic gap exists in providing transportation for community integration activities – jobs, recreation, volunteer activities, social and family visits, etc. Providers are expected to provide transportation for community inclusion activities out of the home support hourly rate without line-item reimbursement.

**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, community supports program, and needed medical appointments as a result.

The 2016 Annual Report identified a number of issues on this topic and made numerous recommendations concerning inappropriate behaviors by drivers, inadequate or unsafe vehicles, weak scheduling requirements, lack of accountability for drivers or brokers, and lack of training for the staffs in dealing with individuals with IDD/ASD. Recommendations included involving internal Quality Management Teams in DHHS, hiring external contractors to review the system, and creating a stakeholder group to redesign the system from top to bottom.

**Recommendation:**

- A system must be funded and developed to serve ***both*** the MaineCare-funded medically-related services ***and*** the community inclusion needs of the IDD and ASD community. Proper training must be provided to drivers so that they are sensitive to the needs of those they are transporting.

The primary goal of community-based service is to provide adults with IDD and ASD the same services and experiences as other community members.

The MDSOAB recommends that DHHS and MACSP (Maine Association of Community Service Providers) strongly consider approaching the Maine Department of Transportation for their assistance in developing a new plan for providing non-emergency transportation for access to MaineCare services and for community integration of those with intellectual and developmental disabilities and Autism Spectrum Disorder. MDOT has a Transit team that works closely with Maine’s 22 regional mass transit providers and, working with a stakeholder group, would bring considerable expertise to the issue.

### 9. Communication with OADS and DHHS

“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.” (From the 2016 Annual Report.) The report described the following difficulties in communicating with the department. Unfortunately, based on the most recent public forums, all the same difficulties still exist today.

**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 communication 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.*

Recently OADS has announced that they will be consolidating their stakeholder group meetings. The stated goals are to reduce redundancy and assure that all groups receive the same information at the same time. These meetings are scheduled to be held in Augusta from 3:00 to 5:00 PM on the last Friday of every third month, which means that the important inaugural meeting will occur on August 31st, the getaway day for the Labor Day weekend. In other years, the date will fall on the Thanksgiving holiday. Asking all stakeholders to travel to a central location at the end of a work week does not seem consistent with the department's stated goal of transparency. A more efficient strategy might flow from meeting with existing groups. For example, OADS has had a standing invitation to attend the monthly meetings of the Maine Coalition for Housing and Quality Services and present any topic of their choosing to a group representing fourteen related organizations. The meetings are accessible in a dozen locations from York to Aroostook counties, with room for expansion to additional sites. Instead of taking advantage of a ready-made stakeholder forum that has been meeting for more than twelve years, the department proposes instead to create a new, and much less convenient, venue. Working with existing groups of goodwill seems far preferable to holding a quarterly meeting at arguably the least convenient time possible, which runs counter to any sense of "transparency."

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

***Recommendations***:

- Work with a contractor experienced in evaluating and modifying text reading levels. Use plain language in regulations, in all publications, and in all communication.
- Ensure that all information impacting the lives of individuals are available in more than one format (i.e. text, auditory, YouTube clips, ADA compatible website).

***Issue:*** Individuals, family members, guardians, allies have difficulty accessing information,

***Recommendations***:

- Ensure that the OADS website is fully ADA-compatible with multiple formats for important information.
- Work with a contractor experienced in Universal Design in web formats to create these pages. Require contractor to work with a stakeholder group throughout the design process.

***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:***

- Develop a process for the transmission of information to ensure that everyone gets the same message at the same time.
- Provide weekly updates via a dedicated web page for both community case managers and providers.

- Work with OADS Quality Management team to identify barriers to timely return of telephone calls. Prioritize communications and returning phone calls.
- Post telephone names and telephone numbers of key people online. Much time is wasted (and much anxiety is created) in transferring calls, leaving messages on answering machines, and waiting for return calls.

## MDSOAB Experience with Departmental Communication

Final versions of new (and radically rewritten) rules pertaining to the MaineCare sections affecting individuals with intellectual disabilities and autism are not shared with MDSAOB prior to implementation. For example, in May of 2018, major rewrites of the rules governing Adult Protective Services and the Reportable Events System were published with almost no notice. Open forums had been held in December, 2017 and January, 2018. The department responded to the comments, as required by statute, and while the department is under no obligation to incorporate any of the recommendations made via the public forums, the new regulations reflected none of the input from the public, and once announced, went into force immediately.

I will speak now of my own personal experience with the communications between DHHS and OADS and the Oversight Board. I first attended meetings of the Board in November of 2016. At that time, the Board was dealing with a possible breach of data that had occurred the previous July. The matter was reported by the Board to the Attorney General's office, and part of the resolution included a non-disclosure agreement, so it is difficult for me to provide specific details here.

Before I retired in March of 2015 I worked for the Office of Information Technology in the Department of Administrative and Financial Services. While employed there, I worked very closely with DHHS on several HIPAA privacy and security matters in my capacity as the state's first Enterprise Information Security Officer. I personally investigated the breach of data at MDSOAB and provided input on the matter to Board members and, through them, to three successive Directors (and Acting Directors) of OADS. I also discussed the matter with the DHHS HIPAA privacy officer. The Board also explained the circumstances to Commissioner Hamilton. Suffice it to say that there was no malicious intent and that no information went any further than the original source of the leak. A breach of privacy occurred, but no other harm resulted: no identify theft, no fiscal loss.

OADS used this event as a pretext to justify not sharing information with the MDSOAB for at least the period from July, 2016 to February, 2018. They refused to provide aggregated data – which contain no personal information and are public records – to the Board, contending that the Board had proven itself unable to maintain control of the data. Finally, OADS agreed to share some information and did, in fact, attend two meetings of the Board in the first quarter of this year. However, their ground rules were that all requests for information had to be submitted two weeks in advance and that they would answer no follow-up questions at the meeting.

Recently – very recently – there have been signs of a thaw in the relationship between OADS and the Board. Acting Director Amy MacMillan attended the July 2018 MDSOAB meeting and had an open and candid discussion of the Crisis Services at OADS. Director MacMillan indicated a willingness to return and participate in focused, single-issue discussions with the Board. MDSOAB is cautiously optimistic that the Department will begin to furnish the aggregate data that will allow the Board to better accomplish its mission to review the services delivered to the IDD/ASD community and to identify systemic problems before they become severe or intractable.

***Recommendation:***

- Introduce a bill to allow a representative from the MDSOAB to access EIS, the department's client database, in order to have direct access to the data needed to carry out its functions. LD 1709 from the last Legislature -- which passed in both chambers, but was vetoed by the Governor -- contained the following language to provide for the privacy and confidentiality of the individuals under care: *"A member of the board or the board's staff may directly access, with or without the permission of the person or that person's guardian, a record that is maintained pursuant to section 5470-B, subsection 7 or section 5605, subsection 15 as long as the member of the board or the board's staff does not further disseminate personally identifying information in the record without first obtaining written permission pursuant to paragraph D. The department shall provide training that is adequate to enable a member of the board or the board's staff to access such a record."* A similar bill should be reintroduced.

## A Final Note on the MDSOAB Contract with OADS

There is an inherent contradiction in an oversight board having its budget administered by the agency it is tasked with overseeing. The Board has both a contract and an MOU with DHHS to provide specific services essential to the functioning of the Department (most notably providing expertise to the Regional Review Teams that review the most restrictive Behavior Management plans). These reviews provide an opportunity to see the system at work, to advocate when necessary, and to spot trends that may need attention. MDSOAB recommends that a structure be devised so that DHHS can review and manage the performance of the contract without having control of the Board's funding, perhaps splitting the function between DHHS and the Division of Administrative and Financial Services.

**Respectfully submitted,**

**Mark Kemmerle**
**Executive Director, MDSOAB**
**August, 2018**

# IV. MDSOAB Annual Report: MDSOAB Activities

## A. Review of Restrictive Behavioral Management Plans

MDSOAB members, designees, and the Executive Director serve on Regional Review Teams (formerly known as Three Person Committees) to review all Level 4 and Level 5 Behavior Plans (formerly known as SIPs or Severely Intrusive Plans) and Safety Device applications. The Review Teams are made up of the OADS regional Crisis Manager, and representatives from Disability Rights Maine (DRM) and the MDSOAB.

New Level 4 and Level 5 plans are reviewed after the first month of implementation, two months after the first review, and then every three months. Once in place, the restrictive Behavior Management Plan (BMP) is reviewed every three months until it is no longer needed. They are intended to be short-term responses to unsafe behavior. There are fewer than 20 of the most severely restrictive Behavior Plans [Level 5] in place as of May, 2018, but over 100 of the next most restrictive category [Level 4].

There are over 400 approved safety device implementations statewide. Safety Devices are re-approved annually.

To ensure the safety and the appropriateness of the plans, MDSOAB members and staff participated in over 60 regional Review Team meetings and reviewed individual plans nearly 1400 times during the year.

## B. Participation on Statewide Review Team

Every member of the Regional Review Teams participates in bimonthly Statewide Review Team meetings to discuss varying interpretations of the Behavioral Management regulations with the goal of coming to a consensus and providing consistency and predictability throughout the state.

During the spring of 2016 new behavioral regulations went into effect. Due to the cycle of reviews and renewals, the members of the Review Teams – OADS, DRM, and the MDSOAB -- are still educating themselves about new requirements, standards, and the interpretation of new regulations. Again, the purpose is to 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

- Rulemaking Comments to the Application for a Section 1915(c) Home and Community-Based Services Waiver, Section 21 of the MaineCare Benefits Manual. Comments on the Supports Intensity Scale and the Qualified Extra Support Services proposals adopted by the Board, August 16, 2016

- Proposed Rule: Chapter 101, Maine Care Disabilities Manual, Chapter II, Section 21: Home and Community Services for Adults with Intellectual Disabilities and Autism Spectrum Disorder – letter from Cullen Ryan for the Board to Andrew Hardy, Comprehensive Health Planner, MaineCare Services. October 28, 2016

- LD 1676: An Act Expanding the Authority of the Maine Elder Death Analysis Review Team To Investigate Deaths and Serious Injuries of Persons with Intellectual Disabilities or Autism – testimony by Executive Director before the Committee on Health and Human Services Public Hearing January 31, 2018

- LD1709: An Act To Allow the Maine Developmental Services Oversight and Advisory Board Access to Investigations of Suspicious Deaths and Mortality Reviews Performed by the Department of Health and Human Services – testimony by Executive Director before the Committee on Health and Human Services Public Hearing January 31, 2018

Members of the MDSOAB also offered written and oral comment on proposed rule changes, including

- 10-149 C.M.R. Chapters 1 and 5, Adult Protective Services – public hearing January 9, 2018 with comments accepted through January 22, 2018. After consideration and response to comments, Chapter 1 (which defines the Adult Protective System) was totally replaced and Sections 11, 12, and 14 of Chapter 5 were repealed (and deleted) effective May 28, 2018.

- 14-197 C.M.R.Chapter 12, Reportable Events System - public hearing January 10, 2018 with comments accepted through January 22, 2018. Chapter 12, which defines the Reportable Events System, was totally replaced, effective May 28, 2018.

### D. Collaboration

The MDSOAB, through its Executive Director Mark Kemmerle and its President/Chairman Cullen Ryan participates in the ***Maine Coalition for Housing and Quality Services***, which provides the meeting room and the remote viewing facilities that allow the Board's Annual Public Forums to reach the widest possible audience.

MDSOAB coordinated planning, implementation, and data collection for its ***Public Feedback Forums***. MDSOAB takes responsibility for analyzing and organizing forum results into topic areas, and for creating a Forum Outcomes Report. See Appendix C for the Executive Summary of the Public Feedback Forum held in June, 2017.

The MDSOAB, again through its President and its Executive Director, participates in the ***Developmental Services Stakeholders Continuum of Care*** group, which meets monthly as an adjunct of the Maine Coalition for Housing and Quality Services to discuss strategies and collaborations with other groups.

## E. The Volunteer Correspondent Program

One of the statutory duties of the MDSOAB is to provide and maintain a Volunteer Correspondent Program. The program was originally designed and organized to support the residents of the Pineland Center, who were moving from an institutional setting to a new system of community-based supports and services.

The Volunteer Correspondent is a person who serves when needed as an advocate for an individual with an intellectual and/or developmental disability or autism, and who offers friendship and a link to the community. Volunteers are just that – that is, unpaid – and they augment the roles of the DHHS case manager, the direct care workers, and the public or private guardian.

Volunteer Correspondents supports the person-centered planning process, access to professional services, a connection to the community, and helps assure a truly individualized program of care and support for a person with intellectual or developmental disabilities or autism. The program was designed to provide support in roles normally filled by family members and is now open to any adult who lacks a private guardian or family member involved in his or her life.

# Appendix A

## Board Membership

***Current appointed members*** as of June 2018: Rory Robb, Jennifer Putnam, Cullen Ryan, J. Richardson Collins, and Ann-Marie Mayberry J. Richardson Collins re-appointment to the Board was declined by the Governor in March, 2018.

***Nominations submitted May 8, 2017 but never acted upon:***: Richard Estabrook, Kim Humphrey, Mark Kemmerle

***Nominations submitted February 23, 2018 but declined by the Governor:***
J. Richardson Collins (self-advocate, re-appointment), Josh Weidemann (self-advocate), Bonnie Brooks (former Board member), David Cowing (parent/guardian)

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

As reported in the previous annual report, the MDSOAB experienced a lack of response from the Office of the Governor from January to December of 2015, when no new members were added. In January, 2016, several nominated members did receive appointments from the Governor. This was the last date that anyone was confirmed for membership on the Board. No members have been appointed in 2017 or 2018.

The three nominees proposed by the Board in May of 2017 for appointment by the Governor were never acted upon. They were not appointed, nor was any explanation ever offered by the Governor’s office. The nominations were ignored.

Four nominees were proposed for membership by the Executive Director of the Board in February of 2018 (two self-advocates, a parent, and a former Board member). Six weeks after the nominations were submitted, the Board received this reply from the Governor’s office (quoted in its entirety):

> Kindly note that the candidates you proffered were fully vetted, however, they were not selected to serve as appointees to the MDSOAB. If you have other individuals you wish to have considered for nomination to the MDSOAB, kindly forward them to Boards and Commissions Director Scott Van Orman who is copied on this email.

All the 2017 and 2018 nominees had been vetted by the Board, attended and participated in meetings while their nominations were being considered (though without voting power), and completed and submitted all the required documentation for approval by the Governor.

As stated in the last Annual Report, the MDSOAB continues to function as a non-partisan advisory board. Political party affiliation is not asked at any point in our nomination process; nor is it remotely relevant to any responsibilities outlined in statute. We seek individuals with great depth of knowledge about services for adults with IDD and autism and a willingness to work hard to ensure that these services become or remain of high quality and great availability. Board members are all volunteers and do not experience any political benefit from their participation. If any issue in the political process is non-partisan, surely it is the welfare of the intellectually and developmentally disabled and those on the autism spectrum.

# Appendix B:

## Public Feedback Forum 2017

### Executive Summary

2017 is the first time the Maine Developmental Services Oversight and Advisory Board (OAB) has used the resources and the cooperation of the Maine Coalition for Housing and Quality Services to host its public forum.

Member organizations of the Maine Coalition for Housing and Quality Services include:

Autism Society of Maine
Maine Parent Federation
Community Connect ME
Disability Activists and Allies of Maine
MACSP
SMACT (Southern Maine Advisory Council on Transition)
Center for Community Inclusion and Disability Studies
SUFU (Speak Up For Us)
Maine Developmental Disabilities Council
G.E.A.R. Parent Network
Maine Children's Alliance
Community Partnerships for Protecting Children (CPPC)
Independence Advocates of Maine
Maine Disability Alerts

The Coalition holds monthly meeting in Portland, with the opportunity for remote participation at twelve locations around the state from Kittery to Presque Isle. The goal of the Coalition is to make the monthly meetings available for remote participation from every county in the state. iton By utilizing the resources of the Coalition, the MDSOAB can reach a large diverse group of people all over the state and share the information gathered at the public forum by published the minutes of the meeting on the Coalition website and linking them from the MDSOAB website.

Then-Executive Director Nonny Soifer presided over the meeting. She stated that the purpose of the forum was "to gather information about the availability, accessibility, and quality of services for persons with intellectual disabilities or autism and their families." Nonny presented a list of topics for discussion, with a ten-minute target for each topic. She also provided contact information so that people could provide additional information, feedback or concerns.

Topics for discussion:

Professional Services (including medical, dental, and therapeutic services)
Adult Protective Services
Crisis & Respite Services
Person-Centered Planning (PCP) and the identification of unmet needs
Access to Services – Waiting Lists
State Guardianship

Inclusion in the Community
Other topics and issues:
Transportation
Internet Access
Transition
Closing of the Pineland Consent Decree

A lightly edited – for clarity and readability - transcript of the comments made at the forum follow as Appendix D.

# Appendix C:

# Public Feedback Forum 2017

## Transcript of Remarks - June 12, 2017

**Topic 1 - Professional Services (including medical, dental, therapeutic services, etc.):** When it comes to chronic disease and/or co-morbid diagnoses, there is a distinct lack of functionally trained medical providers statewide. Often, medical providers are not looking for causes, they're looking to alleviate symptoms – this is not an accurate way to treat the problem.

Medical and behavioral issues follow each other; they overlap. Far too few medical providers have a good grasp on how medical and behavioral issues are interconnected. Unless we do a better job reasonably soon this becomes exponentially more expensive and goes beyond the budget capacity of any state. We will all be better for this, as behavioral issues will decline, and in addition there will be functional improvement.

Across the board we have fewer professionals willing to work in the field, and fewer people willing to take Medicaid/MaineCare funding.

Psychological services, communication services, and dental services are all important, and there is currently a distinct lack of access to them. People travel extreme distances to access many services. At one time, people had to travel all the way to Bangor to have access to sedation dentistry. Now, thankfully, there is a dentist in Portland providing this service.

Lack of access to pediatric cardiologists in conjunction with dental care is problematic.

People have a hard time finding speech therapists for more than one or two appointments.

Occupational therapy has been inconsistent as well, with appointments scheduled so infrequently it's very difficult to make progress. Communication services are imperative; they need to be emphasized and supported.

The curriculum for medical professionals doesn't appear to cover material needed to best provide care for people with ID/DD. This translates to parents having to give an "ID/DD 101" each time they go to the emergency room.

Due to the needs of people and their families, and complexities of the system, services are highly reliant on skilled case management. Case management positions tend to be new graduates looking for a job before they can get a little experience and transition to another job or career path. These recent graduates are just learning about the system about which they're supposed to counsel families; this creates lot of challenges. Case management services ought to be improved so case managers can do their jobs more effectively.

The rate of pay for Direct Support Professionals (DSPs) is too low, which translates to high turnover and agencies having difficulty filling vacancies. People go through numerous DSPs. One parent stated that his son is on his 42nd DSP at the age of 20; having started receiving services when he was 5 or 6 years old, this equates to less than 6 months per person. The wage gap for DSPs needs to be cured so that they can earn a livable wage and be a professional in the field. This would drastically improve direct support services. DSPs would be able to work with people consistently, affording them the ability to get to know the individuals, their needs, desires, and capabilities, while simultaneously understanding the big picture and having the knowledge and history to know when and how to step back and allow for more independence. If DSPs made a professional, livable wage they would be able to stay in the field long enough to excel at their jobs.

The various professional services being discussed can't be looked at separately, as they're very interrelated. If there is a barrier to one, it affects other areas as well.

There is a need for additional, effective training opportunities. Partnering with colleges and universities so that people get experience in the field before they start their career path has proven to be effective where it has been implemented. These types of programs are few and far between, and ought to be expanded. On-going, coordinated meetings and trainings for case managers are needed as well. There needs to be support from the Department for agency trainings for case managers.

**Topic 2 - Adult Protective Services:** Many people reported having had negative experiences with Adult Protective Services (APS).

People outside of the service system -- people in the community -- have had difficulties effectively utilizing APS. The APS system and process is neither clear nor user friendly. When people have successfully navigated the system, follow up has been problematic. Due to confidentiality, APS will not provide information to a concerned community member regarding outcomes of reports made to its office. However, in most instances, people weren't inquiring about outcomes, but rather trying to assure that the information was recorded in the system and given to the proper person for action.

The individuals involved are …for the most part… very caring, but the system is structured in such a manner that allows them to navigate [avoid?] situations about which they're unfamiliar and uninformed.

Over the past several years APS has distanced itself from providers. APS used to work collaboratively with providers in their investigations, sharing information for the best possible outcome. However, now APS does not share information with providers. Information sharing allows for the highest quality outcome.

The Department is currently in the process of reforming the APS regulations, combining them with elder services adult protective regulations. When these regulations are formally proposed, it is feared that they will be stripped down to the bare minimum that's required federally. There was a stakeholders' group when the regulations were being drafted, but there weren't any proposed regulations for the group to react to, so it was difficult to comment. The rule-making process could be improved if there was collaboration from inception all the way through to promulgation. People want to be helpful collaborators, but to participate fully, they need to participate in the whole process and to be informed of all the pertinent details when the Department is establishing new rules.

The Bangor Daily News (BDN) had an article a few months ago [early 2017] that centered on the lack of APS investigations and follow up.

**Topic 3 - Crisis & Respite Services:** It is difficult to find respite providers. Currently there are only two providers in the state authorized to provide respite services. Because [DHHS] made respite a “service” under Section 29, providers have had to apply to provide the service. If you have someone that you used to pay to provide respite, now they must apply at one of the approved agencies and get hired. Compounding this issue is the rate being so low no one wants to provide the service.

There isn’t sign-based respite or crisis services, which affects more than 200 people. When people who communicate via sign language need crisis services they are told to go to the hospital because the hospital provides interpreter services. Then, once they’re at the hospital they tend to stay there longer than needed.

It’s difficult to comment on these services because it’s nearly impossible to figure out what’s available for crisis and respite services. Crisis services is one of the most opaque parts of the Department. Information regarding how many crisis beds there are, how many are provided by the state, and how many are provided by other agencies is not available. People are told to call the crisis number to see if there are services available, and often the answer is that they’re not. Also, when people call the crisis hotline there isn’t someone who can come out right away, and there are never any crisis beds available. Someone can talk to the person in crisis over the phone, but if that doesn’t resolve the issue the individual is left with no option but to go to the hospital.

The Department has stated that it plans to put Emergency Transitional Housing out for RFP since they will no longer be providing that service internally. Karen Mason said at previous meetings that she would follow up with information on this. She also stated last month that even though there might be a crisis bed available, someone might be having a difficult issue where they can’t handle sharing the room with someone else. Thus, a bed might be listed as vacant, but can’t be filled in practice. Crisis providers have commented similarly, that from a capacity standpoint a bed might be vacant but they operationally can’t handle filling that bed. So even though there may be crisis bed “openings,” they’re not actually available for use.

There are no options for someone having a hard time where they could be talked down with the right person or removed temporarily from the house. The only option is going to the emergency room, where often they’ll be over-medicated and/or chemically restrained, which only makes the crisis worse. All it would take is a few more resources and increased capacity to avoid this. There have also been cases where an inordinate amount of resources has been expended to send people out of state for these services. There are fiscal costs for this capacity issue on top of human costs. Crises that could be handled quite readily by trained staff end up escalating exponentially.

**Topic 4 - Person-Centered Planning (PCP) and the identification of unmet needs:** Communication should be addressed first, and almost never is. The process can’t be “person-centered” if the person can’t effectively communicate. Parents aren’t supposed to be driving the PCP meetings, but when the person is non-verbal he or she can’t effectively respond to questions. Often people will just nod along when asked questions, despite that affirmation not reflecting their actual thoughts. There needs to be alternative communication methods, including but not limited to gestural or sign language, available for PCP meetings.

The plan is supposed to be understandable to the person, but rarely is this the case. The plans have become very technical due to the need for them to be uploaded into the Department's electronic system; if you aren't familiar with the jargon it's impossible to follow.

This is another area where more training for case managers is key. There isn't a comprehensive guide or training for how the meeting is supposed to be run.

The justification for need for services has gotten very complex, and as such has become the focus the PCP. Additionally, needs have to be continuously justified even when they have been constants, in some fashion, throughout one's entire life.

There are significant issues with the unmet needs portion of the PCP. People have been told quite clearly that there's no way of obtaining something and it shouldn't be noted as an unmet need. Case managers sometimes decide that if something has been consistently labeled an unmet need for an extended period it should no longer be noted as one in the plan. This skews unmet need data. Additionally, it's important that if there's something that seems to answer the need that the need isn't considered permanently solved, because needs ebb and flow quite frequently, and something that might work right now may not in the future.

The focus of the PCP is too often about inabilities; it should focus more on capabilities. Continually talking about one's lack of ability can be shameful and detrimental.

**Topic 5 - Access to Services – Wait Lists:** It is difficult to believe that there is no one waiting for Section 21, Priority 1. Is it possible that people who would previously have been categorized as Priority 1 are now being categorized as Priority 2? Also, it's difficult to believe there is not a waitlist for Section 29. People have been in a "queue" for months; this constitutes a waitlist. The infrequency of needs assessment/evaluation is problematic. There are likely people who have been on the Priority 3 waitlist for a very long time who might reach the level of need required to be categorized as Priority 2.

**Topic 6 - State Guardianship:** State guardianship is currently in flux. Previously, people under state guardianship always worked with state case management. It will be interesting to see what state guardianship looks like when they're not performing both roles at once. The new system design, with state guardianship uncoupling from case management, could make it more difficult to address problems systematically.

**Topic 7 - Inclusion in the Community:** All the things that have been discussed today relate to and affect community inclusion. In a lot of ways, it's the most important topic to discuss, but it tends to be a lower priority due to the plethora of other challenges. If you don't have the medical services, or behavioral services, or crisis services, or planning services, or case management services, or an effective team process to tie everything together, it's hard to tease out exactly where things start to break down. Everything is very interconnected.

**Topic 8 - Other Topics of Interest:**

**Transportation:** We get used to not having things and you slowly stop talking about them because it becomes status quo – this is the case for transportation. There is a distinct lack of access to transportation and it's dehumanizing. There was a bill, crafted by SUFU (Speaking Up For Us) regarding transportation, but they withdrew the bill. The Department acknowledged difficulties with transportation, but thought the proposed solution wasn't the right fix; the Department wants to sit down with SUFU and discuss this. The Legislature requested that the parties involved report back on this.

**Internet Access:** Lack of access to the internet is an issue as well. The internet is how many of us are included as part of our communities; we maintain linkages through social media and so on. It's hard to imagine real community inclusion without access to the internet.

**Transition:** A cure to a lot of what has been discussed today is through effective transitions. There are a lot of problems that could be solved, or avoided altogether, if there was an effective, systemic way of addressing the transition from school-based services to adult services. The Coalition created a Blueprint for Effective Transition which, if implemented by the Office of Child and Family Services (OCFS) and OADS, would be greatly beneficial.

**Closing of the Pineland Consent Decree:** The courts have concluded the Pineland Consent Decree, and the OAB was established as an oversight body for the Department. There is no vehicle to go back to the courts if the system starts to break down – this was not included in the statutes that established the OAB. Should there be a need, other affected parties can go through the courts to hold the state accountable; this is exactly what occurred which brought upon the Consent Decree.

# Appendix D:

## Public Feedback Forum 2018
### Transcript of Remarks – June 11 and July 9, 2018

Minutes from the July 9, 2018 Meeting of the
Maine Coalition for Housing and Quality Services (excerpt)

Topic: Maine Developmental Services Oversight and Advisory Board's
2018 Annual Public Forum, Part II

**[Sections in blue are from Part One of the Forum, held at the 6/11/18 Coalition meeting, and are included so that all feedback gathered at the forums is available in one place.]**

Present: Ed & Suellen Doggett, Mary Chris Semrow, David Cowing, Mark Kemmerle, Nell Brimmer, Annmarie Mayberry, Rebecca Schroeder, Scott Miller, Bryan Gordon, Betsy Mahoney, Cullen Ryan, and Vickey Rand. Via Zoom – (Auburn): Ann Bentley. (Sanford): Brenda Smith. (Brunswick): Ray Nagel and Colleen Gilliam. (Farmington): Darryl Wood, Joyce Daggett, and Kristin McPherson. (Waterville): Pam Cairnie. Misc. sites: Lori Brann, Kathy Adams, Barbie-Jo Lord.

Cullen Ryan introduced himself and welcomed the group. Participants introduced themselves. Minutes from the last meeting were accepted.

Cullen thanked Senscio Systems, noting that they have very generously covered the cost of lunch for our 2018 meetings! *For more information on Senscio Systems you can visit their* website, *or connect with them on* Facebook *and* Twitter*.*

**Featured Speaker: Mark Kemmerle, Executive Director, Maine Developmental Services Oversight and Advisory Board (MDSOAB). mainedsoab.org Topic: Part Two of the MDSOAB Annual Public Forum**

**Cullen:** Each year the MDSOAB holds community forums across the state to pull people familiar with and/or receiving services together to provide input on how services could be improved, point out issues, and provide general feedback. Last month's meeting featured Mark Kemmerle, Executive Director of the MDSOAB, presenting part one of the MDSOAB Annual Public Forum. However, due to time constraints and robust discussion, not all of the topics were covered; Mark graciously agreed to return today to continue the discussion. I want to welcome you back, Mark, and thank you for this second forum to ensure this group provides feedback on as many areas as possible. As a reminder, this forum is designed to solicit your feedback about how the system of care is working. Input gathered here will inform its annual report. We want to ensure that you all have Mark's contact information (kemmerle.mdsoab@gmail.com) so that you can continue to provide feedback, even after the meeting.

**Mark Kemmerle:** I'm still in the process of writing our annual report, which I hope to complete this month. I've been using the information from last month's discussion for the OAB annual report, from which recommendations for the Department will be made.

**Begin OAB Forum:**
Mark went through the topics individually with the group. The group provided feedback and had thorough discussions for each area of interest covered. The discussion for each topic covered is listed below.

**Topics for discussion** (*-followed by comments from attendees. Italicized sections represent feedback/discussion from the group**. Sections in blue are from Part One of the forum, held at the 6/11 Coalition meeting, and are included so that all feedback gathered at the forums is available in one place.***):

**Topic 1. Crisis Services:** *- The system is slow to identify a crisis. Parents don't have enough education/training regarding how to identify a crisis. Crises can happen incrementally. It's hard for parents to know when their child, or their family, is in crisis because they're so accustomed to dealing with the behaviors, attempting to de-escalate, and comparing the current situation to previous ones where they have been able to prevail, and in comparison, the current situation doesn't seem so bad. In-home support providers can be such great cheerleaders that it can make it even more difficult to known you're in crisis. A parent stated, from experience, that an out-of-state bed can look very appealing, and can better address a child's needs, when compared to the insufficient crisis services in-state. It's very difficult to determine the true number of crisis beds, let alone how many are actually available. The Consent Decree included 24 crisis beds, 12 of which were provided by the Department, and 12 of which were provided by independent providers. However, the independent provider stopped providing this service so the number of crisis beds was reduced. It is believed that there are four homes with two crisis beds each, for a total of eight potential beds. However, due to a number of different rationalizations, it is believed that the functional capacity is a total of four beds. The number of crisis beds is insufficient. The MDSOAB should look into the Department's data collection regarding crisis bed placements and crisis requests. How does the Department know how many crisis beds would be sufficient, even in an ideal scenario?*

*The Department has stated that this information/data is difficult to discern. OADS staff will be providing a presentation on crisis services at the MDSOAB meeting, on Tuesday 7/17. If people have questions regarding this topic for the Department, they can send them to Mark (*kemmerle.mdsoab@gmail.com*). People spend much longer in crisis placements than was likely ever intended. Crisis beds are not long-term solutions – they are temporary, short-term interventions. The State recognizes if a client has additional medical needs by providing the medical add-on, which comes with additional funding. But, there are many people with extreme behavioral needs; the State eliminated the behavioral add-on years ago. Behavioral needs require extra staffing and support, which is not adequately funded. This creates a cycle of people not receiving the support necessary and falling into crisis. Many people with ID/DD also have some type of mental health issue which compounds the problem. The crisis beds are also now shared with people receiving the Traumatic Brain Injury Waiver, which affects capacity. When people can't access crisis beds, the only remaining option is the emergency room. Once admitted, people tend to* *languish in the ER because their needs aren't being met, their crises escalate, and they have nowhere else to go. The Department has stated that crisis beds aren't designed for people receiving Section 21, though this is not supported by regulation. Lack of services, or insufficient services, often directly leads to crisis situations. After falling into crisis, some people inevitably need a higher level of care than they would have previously, because of the crisis and the emergence of new behaviors. Crisis services is spelled out in statute; there are some statutory obligations. If agencies don't contact crisis services prior to the loss of home, it's hard to go back and recreate this documentation.*

**Topic 2. Other Professional Services:**

- **Transition Planning:** *- Parents/families need to be involved in the transition from school to adulthood; they need transition training/planning too as it's just as much a transition for parents. The laws, available services, and ways of individualizing care need to be explained to parents and more information needs to be made available. Transition planning needs to start earlier than age 14; it needs to start as soon as possible. The lack of consistency with case managers is problematic, and it makes it difficult to plan for the future. There isn't enough overlap between children's services and adult services. Everyone needs to recognize that this is one more major leap, and there needs to be people available at the high school level who are really steeped in this information and can work with parents. The terminology is difficult – it's hard for some people to wrap their heads around a "waiver." Voc. Rehab's role isn't clear for many parents. The Workforce Innovation and Opportunities Act (WIOA) has changed Voc. Rehab, and it has a lot of ground to make up. There is not a central information hub during the transition phase. Parents, families, and people supported are in the position of having to become experts about every facet of the system. Transition fairs are wonderful, but then you realize there are 45 different organizations, which is overwhelming. How do you begin to sort through all of that as a parent? Specialists in transition planning are extremely beneficial; the system needs more of them. The school setting gets parents accustomed to having someone take control, set meetings, develop next steps, and so on, whereas the adult system is not setup this way, and it's a shock for parents. The people around this table are arguably the most knowledgeable in the state about the system – if people around this table are confused, imagine how difficult it must be for the average parent or family member to navigate. Even amazing teachers and children's case managers don't have all of the information needed – such as knowledge about waitlists, the potential to utilize and transition to Section 29 services while still in school to help bridge the gap and avoid the cliff of no services, and so on. Even when the people involved know about transition planning, when to start, what to do, and what services to look into, it still can all finally come to fruition too late and still be insufficient. The expansion of Section 29, and the ability to begin the service while still in school, is immensely helpful for transitioning from school to adult services, while avoiding the cliff of no services, and feelings of isolation and loneliness that can manifest when people are removed from the school setting to which they've been accustomed for the majority of their lives. This also helps to avoid loss of skills during transition. The Blueprint for Effective Transition, which this group created and was embraced by both OCFS and OADS at the time of its creation, ought to be fully implemented.*

- **Respite:** *-Parents need to be informed about respite options. No one in attendance has ever accessed respite care, and wouldn't know how to go about doing so should they* *desire/need to. From a parental point of view, you handle your own crises, and there is guilt and shame associated with having your son or daughter's behaviors escalate so they're "out of control." Also, having to air your "dirty laundry" to a bureaucracy, while not knowing what that bureaucracy is going to do, whether it could put your guardianship at risk, etc., is terrifying. This is viewed as a risk for many parents. There should be increased access to respite during the "cliff of no services" period, when people are waiting for services. Perhaps the process for applying for respite services is so complex that few people are able to take advantage of it. In order to paint the picture of need, you're forcing the individual to unpack a lot of things, which can be very harmful.*

- **Behavioral services:** *-The behavior plan regulations, make the submission and review of the behavior plan very difficult. The portion of the plan that's most useful in consumer care is a very small portion of what is submitted for review. It makes the process feel very daunting. It's difficult to find someone who can sign off on behavior plans. It's a challenging service to provide, staff need a much higher skill set, and hiring and retaining staff at this skill level is difficult with the current rates. The rates are insufficient – if someone requires more than 168 hours, the rate is reduced by 12% per hour, it's not incentivized. Homes have been ripped apart by residents, and those costs are absorbed by the agency, because residential contracts don't permit charging the tenant, and the State doesn't reimburse agencies.*

- **Communication:** *-A large portion of people having behavioral issues have trouble communicating them. We need more communication specialists*.

**Topic 3. Wait List Management:** *-If the Legislature overrides the Governor's veto, there's the possibility for 300 people to come off of the waitlist. How will these offers be made? No one is currently waiting for Priority 1, so what are the procedures for making offers for Priority 2? The Department is ten years away from eliminating a 1700+ person waitlist. Many providers are at capacity currently. The queue for Section 29 needs to be transparent. Two-bed homes are unlicensed, so you lose those checks and balances. The Department ought to look at creative solutions to reducing the waitlist such as self-directed waivers and group foster care. A parent presented these creative ideas to Department staff as a way to reduce the waitlist, to which the Department replied that self-directed waivers and funding are being explored by the* Developmental Disabilities Council, *and they did not appear to be motivated to reduce the waitlist.*

**Topic 4. Adult Protective Services:** *-DHHS issued a new set of rules for APS and reportable events (more information on these changes can be found in the June meeting minutes). Once you file an APS report, you don't know what happens next – this has always been an issue but was formally codified in the new APS rules. Anything pertaining to abuse, neglect, or exploitation gets pushed to the 24-hour hotline. After you make the report, your interaction with APS is over. You don't have any access to any information at all. APS reports are no longer in EIS. There might be a note in EIS about abuse, that is very vague, detailing that it came through the crisis hotline, but any information about a potential APS referral is not included. A parent stated that she was informed that staff at her son's group home had left her son alone in a hot, enclosed room with no water last week during the heat wave. The House Manager filed a complaint with the State. In these situations, can the agency simply fire the staff person? Will parents ever find out what happened? What should parents do? Parents can file APS reports as well. It is an* *overwhelming, confusing, complicated system. There are barriers to understanding what you're supposed to do. The system is broken, and all of us are left to pick up the pieces. There needs to be a roadmap for services and the system for parents.*

**Topic 5. Guardianship:** *-There was a complete repeal and replacement of the probate code, which will take effect in July, 2019. The new probate code mandates that least-restrictive alternatives be explored prior to applying for guardianship – such as assistive technology, supported decision making, etc.*

**Topic 6. Case Management:** *-What case management can and cannot do is not well known to parents. A good case manager makes all the difference. Do community case managers duties vary from agency to agency? If you have a more experienced case manager who understands the full scope of the responsibilities and resources available there's a dramatic difference in the quality of the service versus someone who is new to the system, right out of college, and using the job as a career stepping stone. Case management is the luck of the draw. If you have a good, committed case a manager you're golden; if you don't you're out of luck. A good case manager sees the community that's the context in which you're providing the service. A more assertive personality is needed to best provide case management services. The regulations and documentation required of case managers is overwhelming. Many families and consumers don't realize that they can advocate for a different case manager if they're not satisfied with the performance of the one assigned to them.*

**Topic 7. Person-Centered Planning:**

- **Futures Planning:** *-How much control do people have over their own lives? The person needs to be the center of every decision; everything should be self-directed.*

**Topic 8. Unmet needs:** *-Dental care is a huge unmet need. There are about 200 people waiting for a dental appointment with a single dentist in Bangor. I-V sedation dentistry is sorely lacking in Maine – there is finally a provider in the Portland area, after being without one for years. Assistive technology is not utilized to its full potential.*

**Topic 9. Section 29 Services:** *-The expanded Section 29 cap has made a world of difference in a very positive way..*

**Topic 10. Work, and Finding Work:** [This topic was not covered in the meeting. Please send any comments on this topic to Mark (kemmerle.mdsoab@gmail.com)]

**Topic 11. Other Topics of Interest**

- **Transportation:** *-Non-medical transportation is not available, which severely affects community inclusion. People want to participate in community activities but they have no way to get there without access to non-medical transportation. Providers can transport people to community activities, and there is mileage reimbursement. DHHS does not reimburse providers for mileage directly; it is included in the rate. Transportation problems run rampant. People are never sure who is going to show up, or when. People miss numerous appointments, rides show up too early or too late. It's a mess. Using taxis opens the door for exploitation. Getting into an unfamiliar vehicle with an unfamiliar person can be very challenging and can result in behaviors escalating, which can then result in* *providers wanting more staff with the individual. The Department uses a brokerage system for transportation, which includes three transportation brokers, one of which is LogistiCare. The broker agencies are paid a flat fee based on the number of MaineCare recipients in their service areas, rather than being paid based on the number of rides they provide. This does not provide incentive for them to perform well. Agencies often absorb the costs of providing transportation to clients because the regulations are very burdensome. Transportation used to be a line item in the rate, and could be negotiated. Now, it's unclear how the rate truly covers this; there is not a breakdown of the rate. DHHS is involved with transportation for non-emergency medical transportation (NEMT); Maine DOT supports general public trips using a series of transportation providers, like KVCAP, where the ride is subsidized with FTA (Federal Transit Administration) funds. This requires a fare to be paid by the rider.*

- **Inclusion in the Community:** *-There are a lot of ways the system could be streamlined. With the rising costs, and the rate cuts, there just isn't room in the rate for true community inclusion. Agencies are providing for community inclusion; the rates just don't adequately cover it. The Department outlines community supports and home supports. Home supports typically do not include transportation costs. If you have someone receiving home supports who wants to go out in the evening, unless your community supports program is supporting that, you don't get reimbursed for the mileage. Sometimes people confuse community supports, home supports, and community inclusion. The Department is looking at community supports for the community inclusion portion of the individual's life, and home supports for the residential portion of a person's life. There is a dichotomy there and an expectation of families – people living at home should also be able to go and do things in the community, but those things are not reimbursed by MaineCare at all. Home supports do include some community inclusion. When you try to justify any type of extracurricular event beyond the staffing needs of the people in the home, it's not included or even taken into consideration. There are barriers to increased community inclusion with home supports due to the bureaucracy involved with getting staffing approved. There are a lot of people who would not get out in the community unless their home support staff were bringing them out. There needs to be a way to adequately address this type of need.*
- **Communication with Department:** *-The Department ought to participate in regular, inclusive dialogue, through established forums like this Coalition.*

**Cullen:** I want to thank you, Mark, for being here today and last month! Please feel empowered to contact Mark with more feedback (kemmerle.mdsoab@gmail.com). It's important that we continue discussing the challenges with the system, so that we can bring them to light, and put pressure to address them.
*[Round of applause]*
**End of presentation.**

## Appendix E:

### U.S. Department of Health & Human Services
### Office of the Inspector General
### Report in Brief
### Date: August 2017 Report No. A-01-16-00001

## Maine Did Not Comply with Federal and State Requirements for Critical Incidents Involving Medicaid Beneficiaries with Developmental Disabilities

### What OIG Found

Maine did not comply with Federal Medicaid waiver and State requirements for reporting and monitoring critical incidents involving Medicaid beneficiaries with developmental disabilities. Specifically, Maine did not ensure that community-based providers reported all critical incidents to the State; ensure that community-based providers conducted administrative reviews of all critical incidents involving serious injuries, dangerous situations, or suicidal acts and submitted their findings within 30 days; appropriately report all restraint usage and rights violations to Disability Rights Maine; review and analyze data on all critical incidents; investigate and report immediately to the appropriate district attorney's office or law enforcement all critical incidents involving suspected abuse, neglect, or exploitation; and ensure that all beneficiary deaths were appropriately reported, analyzed, investigated, and reported to law enforcement or the Office of the Chief Medical Examiner.

Maine did not comply with Federal Medicaid waiver and State requirements for reporting and monitoring critical incidents for a variety of reasons. Accordingly, Maine did not fulfill many of the participant safeguard assurances it provided to CMS in its Medicaid waiver. Therefore, Maine failed to demonstrate that it has a system to ensure the health, welfare, and safety of the 2,640 Medicaid beneficiaries with developmental disabilities covered by the Medicaid waiver.

### What OIG Recommends and Maine's Comments

We recommend that Maine fully implement its regulations regarding the reporting and monitoring of critical incidents to fulfill the participant safeguard assurances it provided in its Medicaid waiver and help protect Medicaid beneficiaries from harm. Maine agreed or partially agreed with all seven of our recommendations and with four of our findings, but it did not agree with two of our findings. Specifically, Maine disagreed that it did not ensure that community-based providers reported all critical incidents and that it did not investigate or report critical incidents to the appropriate authorities. We maintain that the evidence supports all our findings.

**Why OIG Did This Review** We are performing reviews in several States in response to a congressional request concerning the number of deaths and cases of abuse of residents with developmental disabilities of community-based providers. Federal waivers permit States to furnish an array of home and community-based services to Medicaid beneficiaries with developmental disabilities so that they may live in community settings and avoid institutionalization. The Centers for Medicare & Medicaid Services (CMS) requires States to implement an incident reporting system to protect the health and welfare of the Medicaid beneficiaries receiving waiver services. Our objective was to determine whether Maine complied with Federal Medicaid waiver and State requirements for reporting and monitoring critical incidents involving Medicaid beneficiaries with developmental disabilities residing in community-based settings from January 2013 through June 2015.

**How OIG Did This Review**
We reviewed medical records for selected beneficiaries residing in community-based settings who had hospital emergency room visits and were diagnosed with conditions that we determined to be indicative of high risk for suspected abuse or neglect. We also reviewed critical incident reports contained in Maine's reporting system.

[The "Report in Brief" is an Executive Summary of the complete report.]

A PDF version of this Report in Brief can be found at:
https://oig.hhs.gov/oas/reports/region1/11600001RIB.pdf

A PDF of the complete report (77 pages) can be found at:
https://oig.hhs.gov/oas/reports/region1/11600001.pdf

# Appendix F:

## U.S. Department of Health & Human Services
## Office of the Inspector General
## Complete Report
## Date: August 2017 Report No. A-01-16-00001

**The complete report** (77 pages) titled “Maine Did Not Comply With Federal And State Requirements For Critical Incidents Involving Medicaid Beneficiaries With Developmental Disabilities” and issued over the signature of Inspector General Daniel Levinson can be found online here: https://oig.hhs.gov/oas/reports/region1/11600001.pdf

# Appendix G:

# Joint Report of the
U.S. Department of Health & Human Services
Office of the Inspector General,
Administration for Community Living, and
Office for Civil Rights

**Date: January 2018 Report No. A-01-16-00001**

**The joint report** titled **"Ensuring Beneficiary Health and Safety in Group Homes Through State Implementation of Comprehensive Compliance Oversight"** is a best practices and recommendations document which describes itself as "a roadmap for the states" containing "compliance oversight model practices" and "a toolbox for better health and safety outcomes in group homes." It is intended to provide a model to address the issues identified in the Inspector General's report of August, 2017 (Appendices E and F).

**The full text of the joint report** is 64 pages long and can be found online here:

https://www.acl.gov/aging-and-disability-in-america/joint-report-ensuring-beneficiary-health-and-safety-group-homes