Maine Developmental Services
Oversight & Advisory Board

Annual Report

June 2020 to June 2022

MDSOAB Maine Developmental Services
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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 and autism. It also provides advice and recommendations to the Governor, the Legislature and the DHHS Commissioner concerning policies, priorities, and legistation that affect the lives of those with intellectual disabilities and autism.

The MDSOAB submits this report to the Legislature's Joint Standing Committee on Health and Human Services, the Office of the Governor, and 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 2020), as well as comments from the Public Feedback Forums described in the Executive Summary.

This report covers two calendar years, from July, 2020 to June, 2022.

Mark Kemmerle

Executive Director, MDSOAB

A Brief History of the MDSOAB
Duties and Responsibilities

The Maine Developmental Services Oversight and Advisory Board ("MDSOAB," "OAB," "the Board") was created by the 123rd Legislature in 2007 as ***part of what came to be called "the mechanisms of future compliance"*** legislation.

The history of the Board can be traced back to the class action lawsuit seeking to address the care and treatment of residents of the Pineland Center that was filed in the Southern District Court of Maine in July, 1975. The lawsuit resulted in the settlement known as the Pineland Consent Decree in July, 1978 which was supervised for compliance by a federal master. In November of 1983, the court determined that the state had met the terms of the decree and discharged the special master.

At this time, a citizen advisory board was created, the Consumer Advisory Board ("CAB") to ***provide independent oversight of Maine's system of care for those with intellectual and developmental disabilities***. When the CAB recognized that the State had not kept up with the terms of the decree, the CAB became the plaintiff in a new lawsuit in 1991. That litigation ended with another out of court settlement, the Community Consent Decree, in September, 1994, and another federal master was appointed to oversee the second consent decree.

Part of that second settlement was a requirement that Maine must have a way ***to insure continued compliance with the Community Consent Decree*** before the court could release the state from the supervision of the federal master. The "mechanisms of future compliance legislation" – which included the creation of the OAB – allowed the state to satisfy the requirements of the Court, and the Community Consent Decree was discharged in March, 2010.

Duties of the Board:

The OAB was staffed in 2010 as the successor to the CAB. By statute the Board was created to

> A. Provide independent oversight over programs and services for adults with intellectual disabilities or autism that are provided, authorized, funded or supported by the department or any other agency or department of State Government. ***The board shall focus on systemic concerns*** affecting the rights of persons with intellectual disabilities or autism, including but not limited to issues ***surrounding health and safety, inclusion, identification of needs and desires of persons eligible for services*** by the department, the timely meeting of the identified needs and effective and efficient delivery of services and supports

B. Provide advice and systemic recommendations to the Commissioner, the Governor and the Legislature regarding policies, priorities, budgets and legislation affecting the rights and interests of persons with intellectual disabilities or autism

The Board also provides a representative to each of the three-person Regional Review teams who must ***approve and monitor restrictive Behavior Management Plans*** and Safety Plans. The other members of the review teams are a representative from Disability Rights Maine (non-voting) and an OADS Crisis Team leader. In addition, there is a similarly constituted Statewide Review Panel that makes recommendations to the Commissioner on the Level 5 (the most restrictive) Plans.

Finally, the OAB administers the ***Volunteer Correspondent Program***.

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Executive Summary and Recommendations

In considering the Board's recommendations to the Department for the next year, we reviewed some of long-standing issues that seem to arise every year. Their persistence indicates that the problems are important, difficult to address and remain areas of major concern.

It's very encouraging that some of these issues already have active plans and programs aimed at improving services relating to:

Crisis Services
Transition from Children's to Adult Services
Navigating the System

Others fall under the federally mandated implementation of the Home and Community Based Services Settings rule, which must be implemented by March, 2023:

Community Inclusion
Person-Centered Planning
    Futures Planning
    Unmet Needs

Others seem to be internal to OADS and could be improved by increased focus:

Communication with the Department
Better data sharing

Still others require funding initiatives. In these cases, it is the statutory requirement for OADS to identify unmet needs and to present a proposal to the Legislature for funding to address the shortcomings in these areas:

Wait List Management
Improved Access to Data

The MDSOAB believes that **these five areas deserve special attention**.

1. Expand and improve Crisis Services

The MDSOAB is aware of a small number of people who have been removed from their homes and placed in a crisis home for weeks or months while a new placement is being sought. The usual reason for crisis placement is unmanageable behaviors, generally aggressive behaviors that have in resulted in injuries to staff or to housemates.

The crisis placement is often accompanied by a discharge from the provider. Rarely does a person return from a crisis bed to their former residence. The providers no longer believe that they keep the person – and their staff – safe.

The intent of the Crisis Service system was a temporary intervention, with expert, experienced staff who could help someone in crisis to stabilize and, hopefully, return to their recent placement.

The Community Consent Decree at the closing of the Pineland Center required 24 crisis beds in the system of care. Currently, OADS offers only four two-bed homes, distributed across the state in Gray, North Monmouth, Bangor, and Caribou. When no crisis beds are available in a resident's home region, they are placed one of the other homes in another region, often far from family and familiar surroundings.

When a resident is placed in a Crisis bed, the direct care is provided by the OADS Crisis Team members, which reduces their availability for Outreach (phone consultations, on-site visits, etc. – anything less immediate.

Recommendations:

- Expand the system's capacity for serving residents in crisis.
- Refocus the role of Crisis Services staff to providing training to providers and short-term consultations and interventions. The role of Crisis Services staff should not be to provide direct care, but to help avoid the need for crisis placements, teaching specific techniques for supporting people with challenging behaviors to lessen the need for out-of-home placements.

Observation: OADS has recently entered into a contract with The Center for START Services at the University of New Hampshire to perform a systems analysis of the State's Crisis Services System. For other concerns about Crisis Services, see "The Statutory Requirement to Fund Crisis Services" below.

2. Improve Transition between Children's and Adult Services.

The state's system of support for those with intellectual disabilities or autism has recently raised the age for eligibility to receive children's services through the Department of Education and the DHHS Office of Child and Family Services to age 22. The transition from children's to adult services from and through the Office of Aging and Developmental Services has long been a confusing and harrowing period for many families. Too often, children's case managers are unfamiliar with adult services and adult case managers are unfamiliar with children's services. The handoff from Department of Education to DHHS is too often only loosely coordinated. Due to the large number of people on the waiting lists for Section 21 and Section 29 services, there can be long periods when individuals are not receiving the support they need, and

again, many individuals regress while on these waiting lists and suffer declines in adjustment, social skills, and the ability to function in daily life.

Recommendations: Improve the process for families making the transition between services for children and for adults. Create a joint study group with OADS, OCFS, and stakeholders to identify and address issues in the transition process. Coordinate the transition from the Individual Education Plan in school to the Person-Centered Planning process in adult services.

Observation: In April of 2022, in cooperation with the Department of Education and the Department of Labor, OADS and the Office of Child and Family Services (OCFS) announced an initiative to address the transition from children's to adult services. The idea that the departments of Health and Human Services, Labor, and Education will work together with stakeholders is very encouraging.

3. Reduce the time spent on Waiting Lists. Eliminate Waiting Lists.

In preparing this report, it becomes apparent that these concerns intersect and overlap. Looking for data, the OADS website is hard to navigate. When one locates published data, it's out of date. It's difficult to talk about the severity of a problem when accurate information is unavailable.

The last published Quarterly Report on the Waiting Lists is dated May 7, 2020. It was difficult for OADS to prepare because it required so much manual effort to extract data from its information system. It was evidently difficult to maintain for the same reasons, compounded by the difficulties of the last two years.

OADS as a department says that it maintains sufficient capacity in Section 21 Group Home services to support all Priority 1 individuals (those who are in immediate danger of abuse, neglect or exploitation). In practice, this often means that young adults remain in their parents' homes – with some supports – until one or both parents is no longer able to care for their adult child. According to the May 7, 2020 data, there are approximately 1,700 Priority 2 or Priority 3 individuals who have been identified as being at risk of abuse, neglect or exploration – and thus eligible for Group Home services – but not at imminent risk. Currently, they remain on the waiting list until their situations become more dire. It is important to move Priority 2 and 3 individuals off the waiting lists.

In July, 2018, the Legislature allocated funds to move 300 people from the waiting list into Section 21 group homes. It took over a year and a half for OADS to extend offers to 300 people on the Section 21 waiting list. To our knowledge, no additional slots for those requiring group home support have been approved since July, 2018.

In the last two biennial budgets, the Legislature has provided funding for 30 additional slots per month for Section 29 Home Support Services. This is approximately the

number of new applicants for services each month. The requests are processed as they are received in a “first in, first served” manner. The May, 2020 report showed 369 people on the Section 21 waiting list. There is no data available as to how long one spends on the list, but at 30 offers per month, it would appear that there is approximately a one-year wait.

The delay in the provision of services under Section 29 is an indicator of how far removed the system of care is from providing for Maine residents who qualify for waiver services OADS acknowledges that serious regression is often the consequence of having insufficient care in the transition from children’s services to adult services.

Recommendations: Provide sufficient funds to eliminate the waiting lists within in given time frame to be set by the department and the Legislature. The OAB understands that the Legislature is limited by the biennial budget process, but that is no excuse for a piecemeal process. There needs to be a plan from DHHS and OADS that provides a realistic timetable to provide the services required the Community Consent Decree and by statute. The OAB understands that this can’t be accomplished overnight, but neither can the situation continue to remain unaddressed.

Develop a selection process, with input from stakeholder groups, 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. [Investigation of Reportable Events and APS reports are used to identify those in Priority 1, who are the only ones being served currently.]

4. Improve communications to help navigate the system of support.

Expand use of web services. Redesign website for ease of navigation. Provide more frequent communications and more information on departmental initiatives. Continue the use of stakeholder update calls. Keep published information current. Improve ongoing connection and communication with those on the Waiting Lists, Develop a way outside of EIS to stay in contact with individuals on the Waiting Lists and their families.

The “rate controversy” outlined in Appendix G is a good example of how faulty communication makes everything more difficult for all concerned. The provider network feels aggrieved that no public hearing was held and the rate setting methodology was never clearly explained. The agency feels underappreciated for all the effort expended to provide the funds for a substantial increase in the rate and to the wages and benefits of Direct Service Professionals. See Appendix G for more – though by no means exhaustive – detail.

5. Improve Availability of Data

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. DHHS has been developing and implementing a new information system (Evergreen) since 2016 or earlier (with releases in 2019 and 2020, and a third scheduled for late summer 2023). The OAB has longstanding requests for data from OADS that date back years. Although required by statute to provide data on a regular basis to the MDSOAB, OADS has been unable to comply to any significant degree. A sample of the data requested is included as Appendix E to this report.

Provide up-to-date and accurate information on all aspects of the Waiting Lists, especially those individuals classified as Priority 3.

Three Other Areas of Concern

6. The Statutory Requirement to Fully Fund Crisis Services

There is consensus, both within DHHS and among recipients, providers, and other interested parties, that the crisis "system" in Maine, as it now exists, is itself in crisis. OADS has entered into a contract with the START Program at the University of New Hampshire for a complete system analysis. We suspect that they will conclude that current resources are grossly insufficient to meet the needs of Maine's citizens with intellectual disabilities or autism. The evidence of this is widespread. It includes people being housed out of state for services, numerous emergency planning meetings, and people stuck in hospital emergency rooms for extended stays. Too often persons served, DHHS personnel, guardians, and providers all struggle to find treatment and residential options for persons who for various reasons cannot remain in their home, program or employment because of personal crises.

One of the most basic issues is lack of crisis bed capacity. For approximately 8,000 people in the system of care, there are only four two-bed state run crisis homes. Not infrequently these homes are able to serve only one person because of the severity of the person's behaviors. In addition to the lack of available crisis beds, the system lacks capabilities in professional clinical diagnosis, intervention, treatment, and crisis prevention. Despite their good will and professional competence, the state crisis workers' jobs appear to be nearly impossible. They appear to be completely overwhelmed both by the severity of the issues presented and by the lack of resources which they can bring to bear.

The Department of Health and Human Services has a legal duty to provide crisis and respite services to persons with intellectual disabilities or autism. *See* both 34-B §5201(7) and §5206(1) and (2), particularly the latter:

> "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. Such capacity ***must*** include: (A) Assessment, consultation, planning, training and support…; (B) Providing staff support to prevent or respond to a crisis at the site of the crisis when appropriate; (C) Ensuring mental health supports when necessary, including access to a licensed mental health provider, inpatient treatment when indicated, psychiatric services and mental health aftercare services; and (D) Identifying appropriate professional services for the person in crisis."

and

> "The department ***shall*** maintain an adequate capacity to provide out-of-home safety and support by trained staff with appropriate professional backup resources… for a person experiencing a crisis that cannot be safely managed at the person's residence; Unless otherwise specified… crisis intervention services ***must*** be provided at a person's home, program, or workplace when prevention efforts are not successful. The services ***must*** assist with admission to an appropriate out-of-home service in the event that intervention in the home, program, or workplace is inappropriate."

In this manner, § Section 5206 defines the crisis services to which adults with intellectual disability and autism are entitled.

Both §5201 and §5206 were enacted as part of the "mechanisms of future compliance" legislation in 2007.The Community Consent Decree (§IV(7)) required the state of Maine to have "mechanisms in place to assure future compliance" with the Decree, prior to the termination of the Decree. (*See* LD 1907, 123rd Maine State Legislature) The intent of this legislation was to prevent the "backsliding" that had occurred in the state's compliance with the Pineland Consent Decree. The "Summary" section LD 1907 states: "This bill incorporates into Maine Revised Statutes, Title 34-B some of the provisions required for compliance with the consent judgment… by specifying the ***DHHS's obligation to provide… crisis services…***" The language of §§5201 and 5206 was negotiated by and between the parties to the Decree under the supervision of the special master.

Section 5206 also required the department to implement rules to implement the provisions of §5206. (*See* §5206(8)). The Department did not promulgate rules until July 1, 2021. (*See* 14 Code pf Maine Regulations Ch. 6). This was a delay of over thirteen years from when the requirement was enacted. The language of the regulation tracks the statute fairly well, with one glaring exception. Section 6.03(1) of the regulation twice uses the words "subject to available resources" to limit the "capacity" of crisis services that is required by §5206. The exception completely undercuts the entitlement to crisis services set out in §5206 and

§5201(7). The practical impact of the insertion of these words into the regulation thwarts the intent of the statute.

There is no mention of crisis services being "subject to available resources" in §5206. By promulgating this regulation, the State of Maine has reneged on the promise it made to people with intellectual disabilities or autism and to the federal court in the Community Consent Decree that backsliding in future compliance with the Decree would not occur. **The MDSOAB calls upon the Department to expunge the words "subject to available resources" in the regulation, or, in the alternative, for the Legislature to require that the Department expunge those words from the regulation.**

Unless and until the controlling standard of crisis services is restored to the requirements that are set out in §5206, and not diluted with the regulation's words "subject to available resources", Maine's citizens with intellectual disabilities or autism will continue to be sent out of state for services, find themselves homeless, or be relegated to long stays in hospital emergency rooms.

7. Reduce, then eliminate Out-of-State Placements

OADS reports that there are currently (June, 2022) thirteen individuals with intellectual disabilities or autism who are in out-of-state placements. These are essentially "last resort" placements, made only when in-state providers have been unable to provide proper care. This does not seem to be an excessively high number unless you measure it against the state's goal that no citizen will have to leave the state to get appropriate care.

It is hard for the MDSOAB to get a true picture without historical data. How many out-of-state placements did we have in June or 2021? June of 2020? It's also difficult to evaluate the placements without more personal information that may infringe on an individual's right to privacy or confidentiality.

One measure that would help the MDSOAB in this matter would be a formal agreement on the sharing of confidential data, which could include data that were redacted to remove personally identifiable information. The Board could get a much better picture of the department's performance if it knew why people were placed out of state, how long they have been in out-of-state placements, how long the average out-of-state placement lasts, what kind of treatment they were receiving that was not available in Maine, etc. Until there is better information sharing, we're unlikely to get a true third-party view of the department's performance in this area.

8. Concerns about the Closing of Group Homes

The MDSOAB is concerned about the closing of a number of group homes during the pandemic. Some providers have sold properties and consolidated residents in slightly larger homes with minimal impact, but we know that getting a new home into service is a very costly proposition. And if a person's best placement was in a two-bed home, then moving them to a three-bed or four-bed facility may be an abridgement of their right to care and support in a "least restrictive environment."

As with Out-of-State Placements discussed above, it's hard to get a true picture of how severe or dramatic this trend might be without better historical data. We can get a snapshot of the current situation, but we don't have linear data that will show whether the current trend is unusual and alarming, or something less.

Here are some data received from OADS this month (June, 2022):

> There were 37 closures of Licensed Group Homes for individuals with intellectual disabilities or autism in the eighteen months between December, 2020 and June, 2022.
>
> Those closures are spread across twelve counties: Androscoggin (6), Cumberland (5), Franklin, Kennebec and York (4 each), and Aroostook, Lincoln, Oxford, Sagadahoc, and Washington (1 or 2 each).
>
> The primary reason given for the home closures was "unable to secure sufficient staffing." Four homes were closed because the landlord sold the building. Three single- person placement homes were closed – two when residents chose to move, and one when the individual passed away. All together these home closures directly impacted 55 residents.
>
> Of the 37 home closures - eighteen were reported as permanent closures, five were temporary (agencies kept their licenses), and the remaining 14 homes were not identified as either permanent or temporary closures.

OADS' regulations stipulate that no home may be closed until all its residents are placed in a new home. Many of the residents displaced remain with the same provider and move into an empty bed in another home. Some switch providers in order to remain close to family, but in doing so, they lose their familiar surroundings and the support staff with whom they often have long-standing relationships. OADS reports that they have issued licenses to new providers during this time period and that there has been no net loss of beds in the support system. However, there is evidence that not all of the new providers have experience in running a support organization. They may be experienced care givers, but without any experience in policy administration or many other aspects of running a complex business.

In addition, it would be useful to know how many providers are housing residents that cannot find a new placement despite multiple vendor calls for a new placement. In these cases, the provider feels that the resident is beyond their capacity to serve, but the resident has no alternative but to remain. The crisis system offers no alternative. In such a situation both resident and provider are held hostage by a system that lacks flexibility.

Again, we need better data sharing to help us get a true understanding of the problem. Moving to another house after a landlord sells a long-term residence can be unsettling, but it's hard to say what could be done about it. A group home closing in northern Maine is likely to be more impactful than one in southern Maine just because there are fewer options close by for the family. The state is committed to providing choice in housing, and it may be that alternatives to group homes could also help address the problem of closures. Still, the more homes close, the fewer the choices for residents and their families.

The recent announcement that Sweetser will close some 25 group homes in the Bangor and Belfast areas is cause for much concern. About 45 residents and 130 staff will be affected. MACSP (Maine Association of Community Service Providers) and OADS are committed to finding appropriate placement for residents and staff by the end of year.

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Prior Recommendations and Outcomes

It should be noted that many good things have begun to take shape in the past two years, despite all the adversities that had to be overcome. The Office of Aging and Disability Services (OADS) had to completely rearrange its priorities to deal with the COVID pandemic and the workforce shortage that made it all the more difficult to cope with. OADS also had to implement the federal Home and Community Based Services Rule, which will go into effect in 2023. As much as they might have liked to address the issues raised two years ago – many of which were long-standing – we realize that they were not free to set their own agenda, and despite difficulties, have accomplished much and set much more in motion. OADS's April 25, announcement on the Governor's Supplemental budget 2022 – included in this report as Appendix E -- gives a good idea of the department's priorities, the progress made and plans for the future.

Below is a summary of recommendations made in March, 2020, just prior to the disruption of the pandemic, and the department's related actions.

Recommendations of March, 2020

Increase Rates and Reimbursements.

A) Support legislation that sets pay for **Direct Care Workers** at 125% of the minimum wage and provides indexing to keep pace with raises to the minimum wage.
B) Support legislation to create a reimbursement rate structure for Direct Care workers that allows for incremental pay increases and **differential pay rates based on training and experience**.
C) Support legislation to increase the reimbursement rates for **targeted case managers.** Overloading case managers contributes to turnover. Case manager turnover contributes to problems navigating the system.
D) Create a reimbursement structure that recognizes the costs involved in supporting **residents with severely challenging behaviors**. We have a differential rate for those with severe medical needs. Funding to make environments safe and for repairs and replacement of damaged property needs to be extended to providers who serve those with severe behavioral needs, or their needs will go unmet.

Action taken: Although it took two years to implement recommendation A to increase wages to Direct Support Professionals, the new reimbursement rates provide substantial increases in wages and benefits. The rates are indexed so that the wage will continue to be adjusted to 125% of the minimum wage. Some federal money provided one-time bonuses for case managers who worked through the pandemic, but none of the Board's other recommendations were addressed.

Improve Transition between Children's and Adult Services.

2020 Recommendation: Improve the process for families making the transition between services for children and for adults. Create a joint study group with OADS, OCFS, and stakeholders to identify and address issues in the transition process.

Action taken:

In April of 2022, in cooperation with the Department of Education and the Department of Labor, OADS and the Office of Child and Family Services (OCFS) announced an initiative to address the transition from children's to adult services. The idea that the departments of Health and Human Services, Labor, and Education will work together with stakeholders is very encouraging.

Increase flexibility and choice within waivers.

2020 Recommendation: Lack of flexibility in the system means that planning that is truly person-centered is difficult to achieve. Similarly, lack of available options means that significant choice is limited.

Action taken: In May of 2022, OADS announced the pilot of a Self-Directed Option in the Section 29 waiver. This grew out of the 2021 OADS Reform Plan that targeted "Innovation" as one of four primary reform goals. Self-direction will allow those receiving services to interview and hire their own support staff, set schedules and wages, and invest (within budget and MaineCare regulations) in assistive technology and accessibility modifications for their homes. The program includes the services of a Support Broker to assist in the hiring and interview process and a Financial Manager to set up the paperwork associated with becoming an employer: taxes, payroll, timesheets, liability insurance, etc.

Promote self-advocacy and full participation in the Person-Centered Planning process.

2020 Recommendation: OADS should conduct a review to determine whether the system is still focused on increasing independence among those served by Section 21 and 29 waivers.

The MDSOAB endorses the concept of supported decision making, and allowing all residents to participate fully in making life decisions. The Board also urges that OADS support full guardianship for those for whom it is the most appropriate option.

Action taken: The Department seems seriously committed to revitalizing the Person-Centered Planning Process. This commitment will be reinforced by adopting the Home and Community Based Services (HCBS) Global Rule adopted by the Legislature.

Recognize the Importance of Case Management.

2020 Recommendation: Unmet needs (as for a Volunteer Correspondent) are often not acknowledged because they require an interim plan and generate extra work for the case manager, which is part of the workload issue, leading to rapid turnover and exacerbating the workload crisis.

Training for case managers and direct care workers needs to recognize the frequency of turnover in both jobs. Online modules that cover all the basics need to be made continuously available and be kept up to date. Classroom instruction needs to be provided on a regularly scheduled basis across the state to supplement self-paced, computer-based training.

Action Taken: This remains an area of concern. More must be done to reduce the turnover of case managers. More is being asked of them as part of the effort to smooth the transition from children's services under the Department of Education to adult services in DHHS and OADS. The state must fund a competitive wage to help retain these very important workers. Much attention was paid to the Direct Support Professionals who provide first-line support. It's now time to focus of the importance of the role of the case manager and assure that we develop and retain dedicated and experienced professionals in this area. The importance of the role of the case manager was the center of much of the discussion in the recent June, 2022 Listening Forum, a transcript of which is included in this report as Appendix D..

Support the Volunteer Correspondent Program.

2020 Recommendation: In 2019, the VCP has received updated information from OADS for 1038 individuals who were matched with a Volunteer Correspondent or who had been identified with an unmet need for a Correspondent. The department provided current addresses for the consumers, case manager/agency contact information, and guardian(s) contact information. Approximately 30% of those in our files were found to be deceased, many of whom were members of the class action suit that led to the closing of Pineland. The VCP database has been updated to reflect the date of death provided by OADS and the folders have been removed from the active files.

For living members, their current case managers have been contacted to learn whether there is still a need for a Volunteer Correspondent. From early returns, the case managers have indicated that approximately 25% do not need a correspondent at this time, due to strong family involvement, or a correspondent who has become a guardian, or because the individual has stated that they do not want correspondent involvement. The VCP database is being updated as case managers respond.

The VCP has followed up existing matches with Status Update letters, requesting that the correspondent return a short form reflecting their involvement and the needs of their match. Included in the mailing is a current job description to provide information around

what is expected from a Volunteer Correspondent. Sending these annually will be a way to verify correspondent activity and keep contact information current. There are 84 Volunteer Correspondents with both an active status and current information on file. There are another 163 whose status is somewhat less certain. These are being contacted and as the correspondents respond, their files are updated, and information is tracked in the VCP database.

2022 Status: The Board has formed a subcommittee to study the past and future activities of the Volunteer Correspondent Program. The program coordination resigned in the fall of 2021 and has not yet been replaced. For much of the past two years at many locations, face-to-face contact with those in group homes was either not permitted or took place only outdoors or in other unfamiliar situations.

As before, we still need more new volunteers, with more emphasis on recruiting correspondents and publicizing the program, which we will undertake in the next biennium. We hope that OADS and case managers will be able to take an increased role in identifying residents who could benefit from a Volunteer Correspondent and helping to identify and recruit from natural supports in the family and community.

Support appointments to the MDSOAB.

2020 Recommendation: The Oversight Board has been operating for almost the last three years without most of the participants having been formally appointed. We have been assured by the Governor's Department of Board and Commissions that this is acceptable and does not de-legitimize any of the Board's activities or funding. Still, all those who have been serving on the Board would like the formal acknowledgement that they are serving the Legislature, DHHS, and the IDD/ASD community. The Board would like to request that Office of Aging and Disability Services join us in formally urging the Governor's Department of Boards and Commissions to expedite all pending appointments and reappointments of MDSOAB members.

Action Taken: None. No new nominations to the Board were approved. The Governor's Office of Boards and Commissions was focused on appointments that required confirmation by the Legislature (confirmable appointments), and as far as we can determine, no "Personal Appointments" (those not requiring approval by the Legislature) have been made.

Appendix A

Board Membership

Current appointed members as of June 2022: Rory Robb, Jennifer Putnam, Cullen Ryan, and Ann-Marie Mayberry. (All these appointments have lapsed, but the members continue to serve, as permitted in the by-laws of the Board and confirmed by the Governor's Department of Boards and Commissions.

No new Board members have been confirmed since 2016. The makeup of the Board since November, 2017 has been:

Bonnie Jean Brooks (guardian, former provider)
Kim Christensen (self-advocate)
J. Richardson Collins (self-advocate)
David Cowing (parent/guardian)
Rachel Dyer (representative from the Developmental Disabilities Council)
Richard Estabrook (advocate)
Kim Humphrey (parent/guardian)
Mark Kemmerle (parent/guardian)
Amy Madsen (self-advocate)
Ann-Marie Mayberry (parent, provider)
Jennifer Putnam (provider)
Rory Robb (guardian, former provider)
Cullen Ryan (parent/guardian)
Josh Weidemann (self-advocate)
Lauren Wille (representative from Disability Rights Maine)

As reported in the previous three Annual Reports, the MDSOAB experienced a lack of response from the Office of the Governor from January to December of 2015. 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.

As stated in the last three Annual Reports, 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 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

Prompts for Public Listening Sessions

Maine Developmental Services Oversight and Advisory Board (MDSOAB)
Listening Session – June 13, 2022
In conjunction with the
Maine Coalition for Housing and Quality Services

OADS (The Office of Aging and Disability Services) and their providers have spent much of the last two years dealing with impact of COVID, stopping the spread of the coronavirus and getting thousands of residents and staff vaccinated and done a remarkable job. During this time, a severe shortage of Direct Support Professionals has put additional pressure on families, providers and on those receiving services whose lives have been disrupted.

OADS and the providers have also had much work to do to come into compliance with the federal Home and Community Based Services (HCBS) Settings Rule during this time. As you may be aware, this rule was passed in 2014, but Maine did not start to deal with it until 2019, when the Mills administration took office. As a result, both OADS and the service providers have had to cram seven years' worth of work into two. The implementation and compliance date has been pushed back several times and now is set for March 2023, and questions still exist concerning how all the provisions can be implemented in view of the severe shortage of qualified support staff.

All these efforts required a great deal of work from OADS staff and from all the state's providers, and I think it's remarkable how much has been accomplished. However, there are always issues that persist and still need to be addressed.

Please respond to the following prompts concerning the performance of both the provider community and DHHS/OADS in the past year and of goals and priorities for the future.

1. **What things have gone particularly well and deserve our acknowledgment and thanks?**

2. **Have new issues arisen in this past year that have gone unaddressed due to the unusual demands on the system?**

3. **Some issues come up year after year at these listening sessions:**
   - **Stabilizing the work force**
   - **Transportation**
   - **Crisis services**
   - **Transition from child services to adult services**
   - **Communication**

- **Navigating the system**

Which of these areas of concern should be addressed *immediately* as the Department has breathing room?

4. **Do you have a specific plan or proposal that - if implemented – would dramatically improve an area of service?**

5. **I believe almost everyone would agree that the biggest issue in service delivery in the past year has been the shortage of qualified direct care workers. Any specific suggestions on recruitment and retention of direct support professionals would be appreciated.**

Mark Kemmerle
Executive Director
Maine Developmental Service Oversight and Advisory Board

Please feel free to contact me via email at kemmerle.mdsoab@gmail.com if you have further thoughts.

Areas of focus in previous listening sessions:

Crisis Services, including Respite Services
Transition Planning
Communication with the Department
Navigating the System
Wait List Management
Community Inclusion
Adult Protective Services
Guardianship/Supported Decision Making
Case Management Services
Person-Centered Planning
    Futures Planning
    Unmet Needs
Section 29 Services
    Work, and Finding Work
Transportation
Access to Dental Services
Out-of-state Placements
Access to Data, Transparency

OADS Reform Grid - 2021

1) Community Membership

a. Implement HCBS settings rule
b. Focus on better transition to adult services
c. Improve opportunities for employment
d. Address longstanding issues in transportation

Your experiences in these areas? Suggestions?

2) Quality Assurance and Quality Improvement

a. New QA positions to monitor outcomes
b. More quality monitoring of providers
c. Develop metrics for value-based payment

What are meaningful measurements of quality?

3) Innovation

a. Crisis services – increased focus on prevention
b. More kinds of support for families
c. Increased options for shared living
d. Promoting self-direction
e. Selection of a standard assessment tool

Is there something missing in our system of care? Where do we fall short?

4) Communication

a. Establish strong working relationships with external stakeholders
b. Improve data reporting and data sharing
c. Provide redundant channels of communications to better serve all

Do you feel like OCFS and OADS communicates well with you? What, if anything could be improved?

Appendix C

Minutes from Public Listening Forum, June 14, 2021

Cullen Ryan introduced himself and welcomed the group. Participants names were read by Cullen to save time. Minutes from the last meeting were accepted.

Featured Speaker: Mark Kemmerle, Executive Director, Maine Developmental Services Oversight and Advisory Board (MDSOAB). mainedsoab.org Topic: MDSOAB Annual Forum – feedback for DHHS, including feedback on the availability, accessibility, and quality of services for persons with intellectual disabilities or autism and their families.

Cullen: Each year the MDSOAB holds community forum(s) to pull people familiar with and/or receiving services together to provide input on how services are working well, how they could be improved, and provide general feedback. Today we have Mark Kemmerle, Executive Director of the MDSOAB. I want to welcome you and thank you for being here. This forum is designed to start a dialogue. This year will very similar the past few years' MDSOAB annual forums, with a handful of identified questions/prompts on which the group will focus and comment. We want you all have Mark's contact information (kemmerle.mdsoab@gmail.com) so that you can continue to provide feedback after the meeting as well.

Mark Kemmerle: We've been holding annual forums here for about four or five years. Two years ago, we were able to have listening sessions in person in Bangor and Lewiston, which were very well received. We couldn't do that last year due to COVID. I'm hoping by fall, when people are more comfortable gathering in person, we can get back out and go to the families and the people receiving services and listen and receive feedback about the services they receive. When you look at the feedback received about issues, it's very similar year-to-year. It's been a tough year for OADS (the Office of Aging and Disability Services) and for the service providers. OADS has been under a lot of pressure to deal with stopping the spread of the coronavirus and getting thousands of residents and staff vaccinated. And, OADS and the providers have also had much work to do to come into compliance with the new federal Home and Community Based Services (HCBS) Settings Rule. All these efforts required a great deal of work from OADS staff and from all the state's providers. In light of these challenges, many issues may have gone unaddressed because there just was not capacity to address them given everything else requiring immediate attention. Please respond to the following prompts concerning the performance of both the provider community and DHHS/OADS in the past year and of goals and priorities for the future. The more specific people can be with their feedback and suggestions, the better.

Forum Discussion: *The following includes a numbered/bulleted list of initiatives and questions for consideration. The direct feedback generated from attendees follows each prompt, and is italicized, with any responses to questions/comments indented and identified by the speaker, as relevant.*

1. What things have gone particularly well and deserve our acknowledgment and thanks?
Provider agencies and OADS did a fine job keeping people safe during the

pandemic. It was incredibly difficult for agencies to keep their doors open and continue with business as usual during the pandemic, and they were commended for doing so.

The additional funding to increase DSP wages during the pandemic was very helpful.

Providers and OADS showed a lot of creativity, flexibility, and innovation and responded to situations extremely quickly.

The weekly OADS calls have been extremely helpful for information sharing and transparency, and hopefully they continue even after the pandemic.

The DSP workforce crisis was heightened during the pandemic, and it was a huge loss. DSPs who stayed in the field deserve a large reward for their tireless efforts and dedication.

2. Have any new issues arisen that have gone unaddressed due to the unusual demands on the system in this past year?

So much time was spent doing damage control that opportunities were lost to help people stay connected, have meaningful relationships, and do the things that they were allowed to do. Managing the pandemic, keeping people safe, and understanding what people weren't permitted to do (for health reasons) prevented providers from focusing on what people ***could*** *do, even though they might be in the midst of a pandemic. Life kept going, but opportunities to enrich relationships were missed, especially in the first months of the restrictions.*

Person centered planning (PCP) wasn't particularly rich during the pandemic, and it took longer to focus on the possibilities versus just on what could not be done.

Many people supported through OADS' disability services felt the adverse effects of social isolation and had occasion to access behavioral health services for the first time. As mental health services are administered through a different organizational silo, it would have been helpful to have better support for those with a dual diagnosis (ID/DD and mental health) who didn't know their way around the system.

Technology was successfully used during the pandemic, but there was often a steep learning curve for people who were not tech savvy. Having DSPs who were better able to use technology and who could be more involved in helping the people they support to learn and use that technology would have been a big help.
DSPs often underestimate the capabilities of our loved ones, who often can do so much more than what may appear obvious. Residents ought to be encouraged to participate in using technology.

The DSP workforce crisis was heightened during the pandemic, and it had a huge impact on care and on the quality of many residents' lives.

Mark: In speaking with Paul Saucier and Betsy Hopkins, I know that they're very interested in reaching out to DSPs to determine why people make it a career choice. What is the appeal? What are the rewards? What would make being a DSP an attractive career choice?

Comments from group: *Opening the lines of communication with DSPs would be helpful. There are communication barriers for some DSPs. English is the second language of*

many DSPs – there are both cultural and communication gaps. A parent mentioned that she had read an article recently about DSPs becoming unionized in order to gain better protection and control over their work and their futures. Two providers in the audience noted that some DSP's in Maine are, in fact, already unionized.

3. Some issues come up year after year at these listening sessions:

- **Stabilizing the work force**
- **Transportation**
- **Crisis services**
- **Transition from child services to adult services**
- **Communication**
- **Navigating the system**

Which of these areas of concern should be addressed IMMEDIATELY as the Department has breathing room? Where would you allocate resources?

For Maine Parent Federation, transition is their number one priority. Parents don't know where to get information on transition, as well as guardianship and supported decision-making. They also receive a lot of calls and questions about the waiver waitlists. More information dissemination regarding transition would be advantageous.

Amanda Hodgkins, Children's Behavioral Health-OCFS: *We've heard that feedback repeatedly from people in the community and we're working on getting more information out there through the Resource Guide we're developing. I'm not sure when it will be finalized, but when it's complete it will be well-advertised. The hope is this will be a very useful tool for all.*

The old transition council structure, that mostly went by the wayside except for SMACT (Southern Maine Advisory Council on Transition) was very helpful. It's disheartening to realize twenty years later that parents are still struggling with transition.

Virtual information sessions or ways for families to learn how to support someone with ID/DD and mental health challenges, and for direct care workers to learn how to support people with ID/DD and mental health challenges. Everything is very siloed and people with ID/DD and mental health issues suffered during the pandemic because of this. Coping strategies and supports would be helpful.

Better exploring the overlap of behavioral health and ID/DD services so the system can support people better would be very helpful. In general, the system does not do a good job of supporting people with complex mental health needs because staff are trained on ID/DD. There's little information out there about the intersection with the mental health world.

One provider (Jodi B.) stated that they used an online training program called Open Future Learning which has a number of modules on mental health topics and that her organization far preferred it over the College of Direct Support lessions. This provider also trained some families and paid them under the K waiver.

Lack of summer programming and services is a problem, and often requires parents to take the summer off to provide care for their children. The youngest children and their families often go overlooked, but it's a real problem, especially for the youngest age group 0-3 years old.

4. Do you have a specific plan or proposal that - if implemented – would dramatically improve an area of service?

Cross-training staff on mental health.

A richer person-centered planning (PCP) process that better connects people with unpaid supports in the community. The HCBS Settings Rule will assist with this, but we need more training and expertise in the system.

The Department ought to establish a full-time permanent HCBS Housing Specialist position so there's someone looking at housing innovations being done elsewhere and helping to build relationships with affordable housing agencies and other partners throughout the state so these unmet needs for affordable and supportive housing can be addressed. There is a lack of independent living options for adults with ID/DD. Shared living is a great model that works for many people, but a housing arrangement where someone can live independently with peers in the community would benefit many.

To honor the intent of the HCBS Settings Rule, there needs to be a larger continuum of supportive housing options. We don't need to cut the menu of current models, but we can increase the options available. There's a possibility of looking at others in the community as supports. There may be people who want to live with people with ID/DD – college students, interns, etc. This would expand social awareness and knowledge of the needs of people with ID/DD as well as help to defer cost of living for these people in exchange for natural support services.

5. I believe almost everyone would agree that the biggest issue in service delivery in the past year has been the shortage of qualified direct care workers. Any specific suggestions on recruitment and retention of direct support professionals would be appreciated.

Develop additional strategies to build being a DSP as a profession – helping to repay student loans, paying for ongoing education, etc. to motivate people to get into the field and to stay and grow as professionals. Supporting education in the various ways possible is a long-term investment in professionalizing and increasing the respect for this line of work.

Robust self-directed services would improve workforce capacity in a creative way. DSPs sharing interests with waiver participants, neighbors who have strong relationships with waiver participants, etc., there may be a non-traditional member of the workforce that would be perfectly matched for waiver participants. Self-directed services really allow us to grow the workforce and grow options for more meaningful lives. With robust self-directed services, you wouldn't have to recruit for staff online where people often don't read the job descriptions – that often include those very specific things that members like

to do such as knitting etc., which then affects the quality of services. You could recruit for DSPs at the local churches, knitting circles, book clubs, etc., the places and activities in the community in which members want to actively participate.

Natural supports are hard to come by and they are very unique – so having the Department and the system rely upon them is challenging. The idea of self-directed services, for individuals to go out and seek people to specifically provide the services for which they're looking is a creative one. Natural supports can happen, but they can also change the job of a DSP in ways that we don't always allow for, such as needing a DSP to work an evening shift or two to adapt to the activities in which people want to participate. How do I help them participate in events that are outside of regular business hours and cultivate relationships with people there and slowly back off? This is what's required of a DSP when building natural supports. It's doable, but it can be difficult, and it must be purposeful. HCBS Settings Rule requires this type of service delivery. However, with the current workforce crisis agencies don't have the capacity to do so. Addressing the workforce crisis is paramount, as well as addressing the lack of affordable housing options. We need the structures in place to truly make this happen for everyone.

Cullen: We will be sure that all of feedback provided today is incorporated into the minutes and given to Mark for the MDSOAB. If people have additional feedback on how things are working and how things could be improved please email Mark (kemmerle.mdsoab@gmail.com). Thank you, Mark, for being here today!

End Presentation *(round of applause would have occurred were it not for everyone being muted and on Zoom)*

Later input via email:

Darla Chafin, [parent, advocate]:
Things that have gone well & deserve acknowledgment:

Care by DSPs and group homes during the isolation of the pandemic. It's the first time my daughter and I have been separated for any length of time. She also lost her horseback riding and swimming therapy. There's no question that her abilities have lessened due to that omission, but she has put up with zoom calls and was happy to see me again. As for doctors, it has been difficult, but her staff would say, "I just did was I saw you do and got on the gurney to cuddle her... " and it helped. Favorites have volunteered to see her through such stressful times and ignore the end of the shift. Most importantly, she's smiling.

Issues that come up year after year:

Knowledge and interaction between different parts of system is still a problem. Partially due to the unexpected COVID cash from the federal government and partly due to the reduced staffing problems this year, my daughter evidently went over her cash limit. Not only does she owe a month's rent, but also I'm told [by MaineCare] [that she owes] a fine of $8,000. They say my release for the case manager to handle this was invalid and I would receive a new one the next day. Still not received. The release was made to the agency and this is the first I have heard that it wasn't acceptable. That was several years (and case managers) ago as a result of the State abruptly [phasing] the program out., Maybe we need some basics on who does what, and more importantly when things become invalid.

Just generally, this seems to be going around in circles, and the 15 days for requesting a hearing must be well passed. Others have been caught in this as well. I received a letter on June 3 that effective July 1, Cathy may keep all her income for personal needs and expenses. I am indeed confused.

Kim Humphrey, Community Connect:

1.What things have gone particularly well and deserve our acknowledgement and thanks?
The weekly/bi-weekly covid stakeholder calls were helpful and reassuring. Also when an individual within the I/DD community got Covid the department was very supportive. Thank you.

2. Have any new issues arisen that have gone unaddressed due to the unusual demands on the system in this past year?
Covid exacerbated the workforce crisis. A new issue from the current changes in the I/DD system of care for adults is monitoring the changes and what they mean for the people being served. How much were the lives of people living in group homes, shared living, community programs and waiting lists impacted by these crises, underfunding issues and waits? How many group homes were forced to consolidate, or couldn't provide choice because they couldn't find staff? How many homes are closed or are on the verge of closing? How many people that received waiver slots could not find placements and why? What is the aggregate profile of people that can't find services once offered a waiver slot? How are the people waiting for waivers doing, especially those that need section 21? How many community programs closed or changed the way they do services? Families were paid when they took family members home during the covid crisis. Did funding families while not increasing rates for group homes (except for 3 months) impact the system of care? Did it inspire more people to become shared living providers? If so, how many? What is the impact of that on the existing system and the people being served within it?

3. Some issues come up year after year at these listening sessions: stabilizing the workforce, transportation, crisis services, transition from child services to adult services, communication with the department, navigating the system. Which of these areas of concern should be addressed IMMEDIATELY as the Department has breathing room? Where would you allocate resources?

These priorities are interlinked so that if you stabilize the workforce, you will improve the crisis and make navigating the system easier. Thus, it will be easier to transition from child services to adult services when the workforce is stabilized. With better transition from child services to adult services one also will slow down the need for crisis services. This will help make it more accessible because there will be greater choice within the system. Transportation is long overdue for fixing and it along with the workforce is a priority. But make sure not to diminish areas where transportation works well within the system as part of the formula for fixing what is broken.

4. Do you have a specific plan or proposal that - if implemented – would dramatically improve an area of service?

Ongoing two-way communication between government and stakeholders will dramatically improve the system of care. Communication between areas that usually function in isolation would dramatically improve the system. More communication between departments with a lifespan perspective would help. It is hard to understand how to make the system work most effectively without such an ongoing communication network. It is simply too complex of a system.

Improving the effectiveness of a person-centered planning team and process by providing training, would improve the system of care, as more people would be working together to help individuals reach their goals.

5. I believe almost everyone would agree that the biggest issue in service delivery in the past year has been the shortage of qualified direct care workers. Any specific suggestions on recruitment and retention of direct support professionals would be appreciated.

Increased pay for the workforce is the number one issue, so thanks to the department for the increase to begin in January of 2022 that will keep ahead and above minimum wage. That was essential! In the meantime, there is an immediate crisis to tend to. Use the federal rescue fund to provide bonuses for workforce that have served during covid, that have served for multiple years, or sign on bonuses to help salvage the near system collapse. Secondly, better recruitment and training for the New Mainer communities will improve the service system. Make sure that the native language of the person served is the language spoken by the support staff.

Appendix D

Minutes from Public Listening Forum, June 13, 2022

Cullen Ryan introduced himself and welcomed the group. Minutes from the last meeting were accepted. For the sake of time, Cullen read the names of participants.

Featured Speaker: Mark Kemmerle, Executive Director, Maine Developmental Services Oversight and Advisory Board (MDSOAB). mainedsoab.org Topic: MDSOAB Annual Forum – feedback for DHHS, including feedback on the availability, accessibility, and quality of services for persons with intellectual disabilities or autism and their families.
Cullen: Each year the MDSOAB holds community forum(s) to pull people familiar with and/or receiving services together to provide input on how well services are working, how they might be improved, and to provide general feedback. Today we have Mark Kemmerle, Executive Director of the MDSOAB, to do just that. I want to welcome you and thank you for being here. This forum is designed to start a dialogue. This is one of the primary reasons this Coalition exists – to disseminate information, solicit feedback, and work to make the system of care better for people with intellectual/developmental disabilities (ID/DD) in Maine. This year will similar the past few years' MDSOAB annual forums, with a handful of identified questions/prompts on which the group will focus and comment. We want you all have Mark's contact information (kemmerle.mdsoab@gmail.com) so that you can continue to provide feedback after the meeting as well.

Mark Kemmerle: We've been holding annual forums here for about five or six years. OADS (The Office of Aging and Disability Services) and their providers have spent much of the last two years dealing with impact of COVID, stopping the spread of the coronavirus, and getting thousands of residents and staff vaccinated and have done a remarkable job. During this time, a severe shortage of Direct Support Professionals (DSPs) has put additional pressure on families, providers, and on those receiving services whose lives have been disrupted. OADS and providers have also had much work to do to come into compliance with the federal Home and Community Based Services (HCBS) Settings Rule during this time. As you may be aware, this rule was passed in 2014, but Maine did not start to deal with it until 2019, when the Mills administration took office. As a result, both OADS and service providers have had to cram seven years' worth of work into two. The implementation and compliance date has been pushed back several times and now is set for March 2023, and questions still exist concerning how all the provisions can be implemented in view of the severe shortage of qualified support staff.

All these efforts required a great deal of work from OADS staff and from all the state's providers, and I think it's remarkable how much has been accomplished. However, there are always issues that persist and still need to be addressed. Please respond to the following prompts concerning the performance of both the provider community and DHHS/OADS in the past year and of goals and priorities for the future. The more specific people can be with their feedback and suggestions, the better.

Forum Discussion: *The following includes a numbered/bulleted list of initiatives and questions for consideration. The direct feedback generated from attendees follows each prompt, and is*

italicized, with any responses to questions/comments indented and identified by the speaker, as relevant.

1. What things have gone particularly well and deserve our acknowledgment and thanks?

- *It's been a tough few years and people have been amazed how well OADS, providers, staff, and individuals have navigated and weathered the pandemic and all of its complexities and challenges.*

2. **Have any new issues arisen in this past year that have gone unaddressed due to the unusual demands on the system?**

- *It would be great if OADS could be open to different, alternative housing models.*
- *In previous years high schoolers would stay in school until they turn 20, however now students can stay in school they turn 22. Retention of support staff is even more critical during this time due to the need to build relationships and trust which is lost when there is staff turnover.*
    - **Betsy Hopkins**: We're working with OCFS and looking at transition liaisons to address youth transitioning from children's services to adult services. The LD 924 Task Force is looking at this as well, compiling data, and coming up with specific recommendations.
- *There is often a dilemma for families of children who are in that 19-21 age range regarding next steps – for example whether to accept Section 29 and leave school. These decisions are challenging for families, especially with the workforce crisis and not knowing if there will be someone to provide those Section 29 services should they chose to accept them.*

3. **Some issues come up year after year at these listening sessions: Stabilizing the work force; Transportation; Crisis services; Transition from child services to adult services; Communication; and Navigating the system.**

Which of these areas of concern should be addressed *immediately* as the Department has breathing room? Where would you allocate resources?

Navigating the System/Case Management:

- *Since these topics come up year after year it might be beneficial to provide case managers with additional training.*
- *Case managers turnover so frequently it's very hard, especially for families that need someone to hold their hand and provide good guidance.*
- *Case managers are under a lot of pressure to learn all the facets of the system, especially when there are changes. Case manager reimbursement rates have remained stagnant, to the point where there's a lot of compression – the DSP salaries are catching up rather rapidly to case managers. Case managers are leaving for other, better-paying scenarios. Recruiting and retaining case managers is a challenge.*

- *Knowledge is power. Case managers have to be experts in all areas of the system, and they are not given the status or pay to continue on their professional path as case managers. But they should be that independent voice that helps people and families through the process. Knowledge, communication, and collaboration are key to everything.*
- *For families it's what you don't know that gets you in trouble. Skilled case management solves for this.*
- *It's even more difficult for case managers now because the needs of people coming through the system have changed, there are mental health issues, more complex needs, etc. Training for this would be beneficial.*

Transition:

- *Maine Parent Federation receives more calls about transition than anything else. With the age change for being able to stay in school, people are often not sure what they are eligible for, what their options are, etc. Many case managers don't know this either. Some across-the-board training – where children's case managers and support staff know about the adult work and adult case managers and support staff know about the children's world – would be helpful. It's all very difficult for families to navigate.*
- *For kids in transition, it can be very confusing who helps you apply for waiver services and get on the waitlist, and that causes a delay in applying which further delays receipt of waiver services.*
- *There are multiple school transitions – from elementary school to middle school, and middle school to high school. There ought to be something that can be given to families at the IEP meeting to help educate them about the pros and cons of having a case manager and receiving services.*
- *Transitions are stressful, for the person and the family. It's what keeps parents up at night. This stress and difficulty could be remedied by more knowledge, communication, and collaboration.*

Communication/Information Sharing:

- *Transparency with data is critical – what is shared, what isn't, what's available, what isn't, etc.*
    - **Mark**: When coming up with these prompts I try to think about the areas of the system over which OADS truly has control. The two things that I think that are most difficult for OADS to control are funding the waitlists and building a data system to fully capture and integrate all of the data they have. Having access to data is important, however. A bill that passed the Legislature included improvements to the MDSOAB and improving the exchange of data between OADS and the MDSOAB is included in that bill.

4. **Do you have a specific plan or proposal that - if implemented – would dramatically improve an area of service?**

- *The VR (Voc Rehab) system uses social security numbers (SSN) to identify/track people, but this is not done in other Departments/Offices. This data tracking via SSN is done successfully in other states and would allow Maine to better identify people, deidentify data, and look at trends. The LD 924 Task Force is looking into this as it works on its recommendations.*
- *The Person-Centered Plan (PCP) is key in the adult world. Including measurements/indexes of independence and choice (i.e., Do you vote? Do you make your own choices when you go shopping? etc.) in the PCP would be advantageous for people and would work to make it more person-centered. This would also speak to one's happiness in their lives. Additionally, everyone is different and has different capabilities and desires, so that would have to be built into those measurements/indexes.*
- *Having a list of acronyms and definitions would be helpful for families and would help with communication.*
- *Though they aren't mutually exclusive, sometimes in policy and legislation people and ID/DD are mixed in with "behavioral health." Working to ensure this doesn't continue to happen is important.*

5. I believe almost everyone would agree that the biggest issue in service delivery in the past year has been the shortage of qualified direct care workers. Any specific suggestions on recruitment and retention of direct support professionals would be appreciated.

- *DSPs ought to be paid more – there is a lot involved including trainings, paperwork, etc. Many DSPs need second jobs in order to get by. Summer proves to be especially difficult or DSP staff retention due to seasonal work paying far more than the rates.*

-It was asked if Mark would consider sending this to SUFU (Speaking Up For Us) to solicit their feedback as well.
Mark: I hadn't planned on doing so but definitely can. In the past we used to go on the road and do these forums in multiple locations across the state – in person. Today's listening session is in lieu of an in-person forum. Though, I'm hoping by the fall we can have in-person listening sessions.

-It was asked what the goal is for this forum.
Mark: These listening sessions are for informational purposes and the feedback received and general trends are included in a report that the MDSOAB puts together for OADS. In going through this process, you see repeated themes, and these are not surprises to anyone including OADS. Then, OADS listens to what is said and responds.

Cullen: I want to thank everyone for their comments, and Mark for collecting this feedback. We will be sure that all of feedback provided today is incorporated into the minutes and given to Mark for the MDSOAB. If people have additional comments on how things are working and how things could be improved, please email Mark (kemmerle.mdsoab@gmail.com). Thank you, Mark, for being here today!

End Presentation *(round of applause -- were it not for everyone being muted and on Zoom!)*

Appendix E

Data Request submitted to OADS, May 4, 2018

1. How many people are on the Section 21 waitlist?
    a. How many are Priority 1?
    b. How many are Priority 2?
    c. How many are Priority 3?
2. How many people were new to the waiting list since Jan 1, 2018?
    a. How many are Priority 1?
    b. How many are Priority 2?
    c. How many are Priority 3?
3. How many individuals were awarded Section 21 funding since Jan 1, 2018?
    a. Please list if they were Priority 1, 2, or 3.
4. How many people with a diagnosis of IDD / autism were awaiting a crisis placement in an emergency room at any time during the month of February 2018?
    a. How many in March 2018?
5. What was the average length of wait time in the ER for a crisis placement since January 1, 2018?
    a. What was the longest wait time in the ER for a crisis placement?
    b. What was the shortest wait time in the ER for a crisis placement?
6. Please provide demographic data for questions 4 and 5.
7. What is the Department's plan for meeting its statutory responsibilities for providing crisis beds for people with IDD and autism?
8. What is the average wait time from applying for Section 29 and receiving a determination of eligibility for Section 29 services?
9. How many people were determined eligible for Section 29 services in February 2018? How long in March 2018?
10. How long did each person determined eligible for Section 29 services in February wait from date of application to receipt of eligibility? How long in March 2018?
11. How many people are waiting for section 29 services as of April 1, 2018?

12. How many 29 shared living provider authorizations have been approved thus far?

13. How many consumers have received a decrease in their medical add on hours since January 2018?

    a. What is the average decrease in hours?

14. How many provider appeals has the State received regarding the reduction in medical add on hours?

    a. How many member appeals has the State received regarding a reduction in medical add-on hours?

15. What are the guidelines of the CRT team in determining a decrease in medical add on hours that have been deemed necessary by the PCP team and the medical doctors?

    a. Please provide the policy/procedure used in determining reductions/increases.

16. How many deaths of people with IDD and autism have occurred between January 1, 2018 – March 31, 2018?

    a. How many have been investigated by the mortality review team?

    b. Please provide the policy/procedure used in investigating deaths.

17. Please provide the policy/procedure the Department uses for ensuring the safety of people with IDD and autism living in unlicensed homes.

18. How many unmet needs have been listed across the state and what areas of need are most frequently listed?

Appendix F

DHHS Press Release on 2022-2023 Supplemental Budget

Maine Health Care Services Strengthened by Bipartisan Supplemental Budget for 2022-2023

Maine Health Care Services Strengthened by Bipartisan Supplemental Budget for 2022-2023
4/25/2022

On April 20, 2022, Governor Mills signed a bipartisan supplemental budget that invests $522 million in total funding ($202 million in State General Fund) in the programs run by the Maine Department of Health and Human Services (DHHS). This will enable the Department to tackle some of the state's most pressing problems, including ongoing impacts of the pandemic and Maine's longstanding health care and child care workforce shortages. Five key areas with support through the budget are described below.

COVID-19 and Behavioral Health Crisis Response: While the economic recovery in Maine has been strong, the health system continues to experience strain. This is why the budget includes one-time payments to help providers of health care, long-term care, and behavioral health services.

- $50 million ($14 million General Fund) MaineCare COVID-19 supplemental payment in fiscal year 2023 for hospitals, nursing facilities, and certain residential care facilities. This will help pay for the continued need for COVID-19 precautions – isolation units, frequent testing, higher labor costs, personal protective equipment – as well as caring for long-stay patients with the disease and pent-up demand for other types of care.
- $21.4 million ($15 million General Fund) to providers of Home and Community Treatment, Assertive Community Treatment, outpatient therapy for children and adults, Targeted Case Management, and children's residential services (PNMI-Ds) to help address immediate challenges facing Maine's behavioral health system in the wake of the winter COVID-19 surge.
- $5.3 million ($5 million General Fund) add-on payment in fiscal year 2023 for high MaineCare utilization in private non-medical institutions that care for residents who are older or have disabilities (PNMI-Cs), which have been critical to decompressing hospitals and maintaining the full range of long-term care residential beds.

MaineCare Reform and Improvements: The biennial budget signed by Governor Mills on July 1, 2021 included significant MaineCare payment rate increases to support higher wages for front-line workers and implement data-driven rates studies. The supplemental budget continues this work and expands coverage to children. Separate from rate increases and investments, the FY22 Supplemental Budget adjusted on a one-time basis the MaineCare General Fund appropriation to account for the enhanced Federal Medical Assistance Percentage (FMAP) matching payments, which had no impact on providers.

- $100 million ($35.8 million General Fund) to fully implement biennial budget rate increases to support 125 percent of minimum wages for direct support services, which are more expensive as a result of higher-than-expected inflation, and to accelerate the cost-of-living adjustment for some providers to align with the start of the minimum wage policy on January 1, 2022.

- $21.5 million ($6.4 million in General Fund) to implement rates studies for behavioral health, consistent with bipartisan legislation (LD 1867) to codify a new system for setting MaineCare payment rates that promotes equity, consistency, and transparency.
- $12 million ($3.1 million General Fund) to expand the Children's Health Insurance Program that will improve health coverage for thousands of Maine children.

Child Care. Quality child care is critical to the early development of children and a pillar of a strong economy and growing workforce. The budget builds on the Department's Child Care Plan for Maine that outlines the vision and uses of over $100 million in new Federal funding.

- $12.1 million in General Fund dollars to increase pay for child care workers and early childhood educators, with higher amounts going to higher trained and educated workers.
- $5.2 million in General Fund dollars to increase the Maine Jobs & Recovery Plan initiative to support construction and expansion of child care facilities, helping to address geographic gaps and supporting additional sites across Maine.

Child Welfare: As part of a comprehensive plan to improve Child Protective Services, DHHS has embraced a number of recommendations from Maine's Child Welfare Ombudsman, nationally recognized experts at Casey Family Programs, and others. The budget includes an investment of over $10 million, and separate funding to strengthen the Office of Maine's Child Welfare Ombudsman.

- $2.8 million ($2.2 million General Fund) investment in staff, including an additional 16 caseworkers and three caseworker supervisors dedicated to night and weekend shifts.
- $3.2 million investment ($2.6 million General Fund) to extend and expand the Homebuilders Program to support families.
- $2 million investment of General Fund dollars to expand Family Visit Coaching from a successful pilot to a statewide program.
- $1 million investment of General Fund dollars in the Parents as Teachers Program, allowing it to expand services.
- $822,000 investment to expand access to Kinship Navigators services, to create a Parent Mentor Program, and to create a Child Protective Services' contingency fund.

Workforce and Infrastructure: DHHS is the largest department in state government and provides as well as manages privately delivered services. The budget strengthens its ability to meet its mission by including:

- 62 new positions, including child welfare workers, limited period positions for workers who help verify eligibility for benefits, an Oral Health Coordinator, a new Developmental Disabilities Resource Coordinator to help manage the growth in the waiver programs, new psychiatric nurse practitioners, and a Chief Operating Officer for the Division of Licensing and Certification.
- Several million for infrastructure such as roof repairs at the Dorothea Dix Psychiatric Center and expanded specialized PFAS testing at the State Health and Environmental Testing Laboratory (HETL), and relocation of HETL to a new building.

It is likely that the Maine State Legislature will enact additional legislation affecting DHHS before it is scheduled to adjourn today.

Appendix G

The Controversy Surrounding the Group Home Rate and Wage Increases for Direct Service Professionals

Since the adoption of the Governor's FY22 budget on July 1, 2021, DHHS/OADS and MACSP (Maine Association of Community Service Providers) have been engaged in an ongoing discussion about whether the rate increase is everything that it is presented to be and whether it truly supports a pay rate for Direct Support Professionals equal to 125% on the minimum wage.

OADS' position in the discussion is, essentially, that the reimbursement rate for Agency Home Supports (aka Group Home Rate) was increased from $27.72 to $29.28 effective July 1, 2021 and then to $31.72 effective January 1, 2022, and that this rate effectively supports a wage of $15.64 per hour to DSP's (plus another $8.34 per hour in benefits).

MACSP feels aggrieved because a new methodology (the "Burns" methodology) was used to calculate the new reimbursement rate, and that methodology was never formally adopted and is based on rate studies not specifically keyed to IDD/ASD services. OADS' position is that the Burns data comes from 2018, while the previous methodology (the "Deshaies" methodology) is based on data from 2005. OADS also points out that Roger Deshaies himself has said that basing a new rate on data that old was unsupportable.

Both old and new rates are based on identifying costs in four areas: Wages, Benefits, Program Costs, and Administration. When the original rate was developed, the providers were told how it was calculated and what percentage each category represented of the whole. The Burns methodology provides less funding for Program Costs than did the Deshaies, while it provides considerable increases in funding for Wages and Benefits and a net increase of $4.00 to the total delivered rate.

Historically, it has always been up to the provider to determine how the dollar was spent. Providers never reported their expenditures by category to OADS or to any other agency. If a provider needed to use more for Direct Support Wages than the percentage supported, then that's what the provider did. Of course, this meant that the funds available for Program Costs and Administration were reduced.

In short, the arrangement between OADS and providers seems to have been "Here is the agreed upon rate for an hour of service, here's how we arrived at how you would spend it, but you're free to reallocate it as needed."

For-profit providers are expected to find ways to streamline expenditures in Program Costs and Administrative to make their services sustainable. Not-for-profit providers spend time and effort in fund-raising to cover shortfalls.

An aside: as long as a provider bills 92.5% of their allocated funding, they are permitted to keep the full 100%. During the pandemic, increased federal funding has allowed the providers to keep the full amount as long as they bill 70% of their hours. This has been a tremendous benefit to providers during the workforce crisis, but the funding is due to expire in December, 2022. It also leaves unaddressed the question of whether the persons receiving services are getting all the services they need.

MACSP strongly believes that the new rate does not fully cover the costs of running a group home. While providing additional funding for wage and benefit increases, wages are still short of what seems to be the market for entry level positions anywhere in the marketplace. OADS consistently points to the dramatically increased spending on IDD/ASD services, citing $100 million to fully fund the increase in wages to 125% of the minimum. (See Appendix F.) MACSP counters that the increase relies substantially on reallocating funds and not providing sufficient new monies to cover all the costs associated with providing group home services.

No doubt this is somewhat of an oversimplification. In my role of Executive Director, MACSP regards me as an apologist for OADS, and OADS sees me as a dupe of MACSP, so I must be doing something right. I've tried to do justice to both sides of the question. OADS has stated that they are committed to having a new rate study and developing a transparent methodology for funding group home services. I do believe that both parties are operating in good faith and that they will continue to work together to solve issues of common concern.

Addendum

Here are few pieces that fall into Program Costs: It will give some idea of expenses that aren't covered by the Wage, Benefits, or Administrative Costs.

Overtime wages (which have dramatically increased due to the workforce shortage)

Any non-billable time for the Direct Service Professionals (that is, any time not spent providing direct service) – staff meetings, PCP meetings, HCBS compliance and documentation time, training.

Training – With so many New Mainers in the workforce the time to complete many of the required trainings has almost doubled due to English not being the native language of the new employees. This extra time is costly when CRMA (Certified Residential Medical Administrator) Insulin, Seizure and all the other medical trainings are taught by Registered Nurses (also not covered in the Group Home Rate). There are (unfunded) positions for interpreters needed to bring new employees on board and provide training and teaching in both content and culture. Similarly, interpreter costs for deaf consumers and staff, while rare, must be paid out of programs costs.

Technology costs -hardware, software, internet, security, technology support; tablets for Electronic Visit Verification

Transportation/vehicle costs - purchase or lease, maintenance, insurance

Shortfall on room and board, including maintenance, snow removal, lawn care, etc.

Liability and casualty insurance

Legal costs

Costs associated with of the pandemic

Costs of implementing the HCBS Settings Rule

Unfunded mandates and cost increases accumulated over the years

- Increases in licensing fees
- Increases in cost of require training (College of Direct Support modules)
- New protocols for background checks
- New requirements for data collection and reporting
- Revalidation costs