Maine Developmental Services
Oversight & Advisory Board

Annual Report

July 2018 to March 2020

MDSOAB Maine Developmental Services
Oversight & Advisory Board
Annual Report
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MDSOAB Annual Report 2020

Executive Summary

Recommendations for the Department of Health and Human Services and the Maine Legislature to improve service for those with Intellectual or Emotional Disabilities or Autism Spectrum Disorder.

Increase Rates and Reimbursements.

The Board understands that DHHS/OADS is conducting a rates review. As we also understand, however, that review won't be complete until March, 2021. In view of the current state of the service support system, the Department needs to take more immediate action in four areas:

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.

Improve Transition between Children's and Adult Services.

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.

Provide training and education for families in el-hi years to aid transition to adult services. Explain group homes, shared living options (including the option for families to be shared living providers), Section 29 services, etc.

Work with stakeholders to make the processes involved in Section 21 and 29 more transparent, especially the selection of people from the Priority 2 pool to receive services. The prioritization of those classified as Priority 2 needs to be clearer.

Provide more flexibility in housing options for those entering the adult system.

Increase flexibility and choice within waivers.

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.

Recognize the Important of Case Management.

Unmet needs (as for a Volunteer Correspondent) are often not acknowledged because they require an interim plan and generate work (part of the workload issue).

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. Not all case managers welcome the presence of advocates.

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

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.

Support the Volunteer Correspondent Program.

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.

The VCP continues to process requests for a correspondent and applications to become a correspondent though as a slower pace. In October 2017, the VCP was working on 24 matches, and in October 2019 we processed five. With the cooperation of OADS and better access to contact information, the process has become more streamlined, so requested are being cleared, rather than remaining open through lack of follow-up contact information.

On the positive side, we are not receiving requests from people who don’t have services (for example, Section 29 services and/or no day programs) as we did in previous years. We still need more new volunteers, with more emphasis on recruiting correspondents and publicizing the program, which we will undertake in the next biennium.

Support appointments to the MDSOAB.

The Oversight Board has been operating for almost the last three 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.

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 and autism.

MDSOAB submit 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 2018), as well as comments from the Public Feedback Forums 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.

The processes of the Office of MaineCare Services (which funds all the waiver programs), the Office of Child and Family Services (partner in transition from child services to adult services , and the Office for Family Independence (which determines eligibility) were often mentioned as well.

This report covers two calendar years, from July, 2018 to March, 2020. The Board had intended to file this report in July of 2019, but decided to defer until the new administration of OADS had time to begin to carry out their own agenda and address some of the difficulties and problems in the service delivery system that have been the subject of past OAB reports. The next Annual Report will cover April, 2020 through June, 2021, the end of the first year of the next biennial budget.

Mark Kemmerle
Executive Director, MDSOAB

MDSOAB Annual Report, March 2020
Problem Analysis and Recommendations

Further recommendations for specific action from the Department of Health and Human Services, the Office of Aging and Disability Services, and the Maine State Legislature.

1. Crisis Services

(From June, 2018 OAB Report) ***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.

Status/Findings, March, 2020: Some increased staffing, No additional beds.

The Community Consent Decree at the closing of the Pineland Center 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 with three providers for additional Emergency Transitional Housing. In practical terms, it is often inadvisable to house two residents who are in crisis together in the same house, which reduces the number of available beds to four, widely dispersed around the state (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 or placed in Emergency Transitional Housing.

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. One of the homes has been continuously occupied for three years by only three people, all cared for in "single placement" mode.

OADS recently received budgetary approval to add eight positions to its Crisis Management group and is using the opportunity to revamp its intake procedures. OADS will move from four local intakes with backup provided by Behavioral Health staff, to a state-wide intake structure for IDD and autism, with the staff in all four regions acting as backup for each other. This change will allow an immediate response to a crisis call instead of a call-back within 15 minutes as under the current system and will allow for more Outreach to avoid emergency interventions.

Recommendation:
- Expand the system's capacity for serving residents in crisis.

Recommendation:
- Reinstitute a robust respite care program. Respite beds could be used for crisis beds in an emergency.

Recommendations:
- 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.

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."

From the 2018 MDSOAB Annual Report:
In May of 2018, …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).

> **UPDATE included in 2018 MDSOAB Annual Report**: The Legislature recently (July, 2018) allocated funds to move 300 people from the waiting list into Section 21 group homes
>
> **UPDATE, 2020:** The MDSOAB continues to ask for a better understanding of the process for selecting candidates from the Priority 2 group on the Section 21 waiting list. OADS is hampered by the delayed implementation of their new integrated IT system (Evergreen). OADS also believes that the selection process is not reducible to a formula (a belief not contested by the Board).

Status/Findings, 2019- 2020: Some progress made, more needed

It took over a year and a half for OADS to extend offers to 300 people on the Section 21 waiting list.

The 129th Legislature has before it several bills that would help reduce the number of people waiting for services, specifically:

- **LD 1984** - An Act to Eliminate Waiting Lists for Home and Community-based Services for Adults with Intellectual Disabilities, Autism, Brain Injury and Other Related Conditions

- **LD 1940** - Resolve Directing the Department of Health and Human Services to Increase MaineCare Reimbursement Rates for Targeted Case Management Services to Reflect Inflation

Both bills include provisions for addressing inadequate compensation for direct care workers and community case managers, a major factor in the system's inability to serve all those who qualify for services. OADS has testified against bills that propose raising reimbursement rates for direct care workers and community case managers, arguing that a rate study is under way that will address the issue. However, the rate study is not scheduled for completion until March, 2021, and the matter demands immediate attention.

Existing 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)] and to perform an annual review of MaineCare 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.

In a separate development, in a letter of February 10, 2020, the United State Department of Justice has informed DHHS that they are out of compliance with the Americans with Disabilities Act and the Olmstead decision [Olmstead v. L.C., 527 U.S. 581 (1999)], in a case where the department is failing to provide care in the least restrictive environment to individual approved for Section 21 services. The letter directed the state to take specific actions that have broad implications on the legitimacy of maintaining a long waiting list for services. That letter is included in this report as as an Appendix to this report.

Recommendation:

- The state must assure that pay rates remain adequate to attract, train, and maintain a healthy, skilled labor force.

- 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 – one that does not rely on Reportable Events and APS reports -- to stay in contact with individuals and their families.
- Develop a selection process, with input from a stakeholder group, 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 in small group homes.

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.

3. Section 29 Services

Delay in providing Section 29 services continues to be an issue. The waiting period for Section 29 services is as long as a year as of this writing. As of January, 2020, there are over 1,600 people on the waiting list for Section 29 Services. Of these, almost 500 are receiving no services at all. 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. 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 so that they may either be compensated while not able to work themselves or in order to ensure adequate care for their loved in another home. Shared Living with the parents as providers doesn't require a waiting period, a hiring period, or a training period to help families who opt for this solution.

Recommendation: **Eliminate the Section 29 Waiting List**

In its work session on **LD 1984** - An Act to Eliminate Waiting Lists for Home and Community-based Services for Adults with Intellectual Disabilities, Autism, Brain Injury and Other Related Conditions, the Health and Human Services Committee added three important amendments to the bill.

- Increasing the cap on Section 29 services from $58,000 per year to $70,000, but only for four years - ending 6/30/24.

- Funding all Priority 2 members on the Section 21 waiting list who are currently receiving no services.

- Funding all new people qualifying for Section 29 services (about 30 per month) through June 30, 2021.

The MDSOAB fully supports these amendments. In the February Reform Plan, OADS has committed to end the section 29 waiting list if funding is provided in the Supplementary Budget.

4. Adult Protective Services

For many years, problems with APS investigations were brought up at the public listening sessions held by the OAB. These 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.

Rather than respond with greater transparency, OADS, through the rule-making process, emended section 10-149, Chapter 1 and 5 on Adult Protective Services in May, 2018. All reports to Adult Protective Services are now made directly to the 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 even more difficult for anyone outside APS to learn the disposition of a report.

Recommendation: **Restore/create transparency**

- Emend the rules governing APS reporting to 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.

- 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 also be shared with the MDSOAB.

- Increase staffing so that investigators have time to respond to inquiries beyond responding to reportable events forms.

- Designate an APS staff member to ensure that every inquiry receives a prompt response.

5. Transportation

The OAB changed its format somewhat for its Listening Sessions in 2019. So many of the same issues had been year and year in these sessions that there was little need to bring them up yet again, especially when the OAB knew and DHHS/OADS also recognizes that there are still problems in these areas. Transportation problems could easily have consumed an entire evening's session.

To recap, the issues are the same: 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 one had been requested in advance. 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 and 2018 Annual Reports 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.

As in 2018, the OAB recommends that DHHS 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. DHHS needs partnership with Education, Transportation, and other state agencies to deliver comprehensive solutions for the IDD/ASD community.

6. 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*
- *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.*

These shortcomings aside, in the past year OADS is doing a much better job listening to families and providers than in recent years. OADS sends at least one high-level administrator to the monthly meetings of the Maine Coalition for Housing and Quality Services, a group representing fourteen parent and provider organizations. The meetings are accessible in a dozen locations from York to Aroostook counties and have been a good venue for two-way information sharing. OADS also attends the monthly meetings of the OAB, listening, answering questions and sharing plans and announcements. The Director of OADS also attended OAB Listening Sessions held in Bangor and Lewiston, and many in the audience expressed their thanks for coming to the local meetings and listening to the concerns of the stakeholders.

In the past year, OADS is making better use of their website in an effort to communicate more clearly with the public. They've also utilized stakeholder groups in several instances to work on legislation to increase wages from Direct Support Professionals and Community Case Managers and to gather input for the HCBS Transition Plan.

The MDSOAB continues to have difficulty getting data from OADS on a regular basis. The Board is also rarely notified in advance of major developments (especially ones that reflect negatively on the department), and generally learns of things through the newspapers.

OADS reports that they have been hampered in gathering and analyzing data by the delay of their new integrated information system – called Evergreen – which is replacing three older systems. Most disappointingly, an OADS representative stated at the March meeting of the OAB that providing the data that the Board had requested would not be practicable until the Evergreen was fully deployed. The Board has made repeated requests and emphasized that we would be glad to start with whatever data is most easily available. Over a year into the new administration, we had expected to be at a different place in sharing data and getting a better understanding of the progress being made on important issues like eliminating waiting lists and improving crisis services.

It is clear that DHHS and OADS have much to contend with. They seem to have taken the first year to listen, to study, to prioritize, and to plan for the next two to five years. We hope that the next two years will see more concrete results.

Respectfully submitted,

Mark Kemmerle, Executive Director, MDSOAB
March, 2020

Appendix A

Board Membership

Current appointed members as of March 2020: 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.

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)

Nominations and reappointments submitted in 2019 but not yet acted upon: Rory Robb, Jennifer Putnam, Cullen Ryan, Ann-Marie Mayberry, David Cowing, Kim Humphrey, Richard Estabrook. There are four Board members, also not officially appointed, who receive waiver services and have served on the Board for over two years: Kim Christensen, J. Richardson Collins, Amy Madsen, and Joshua Wiedemann.

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

As reported in the previous two annual reports, 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, 2018, 2019 or so far in 2020.

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.

In February, four nominees were proposed for membership (two self-advocates, a parent, and a former Board member). Six weeks after the nominations were submitted, the Executive Director of 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 two 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:

Public Feedback Forum Prompts 2019/2020:

”Propositions for a Continuum of Care”

Prepared by the Developmental Disabilities Continuum of Care Work Group

Background: The MDSOAB has conducted public listening sessions each year since the Board was formed. When I became Executive Director in April of 2018, my first tasks were to write an Annual Report and conduct the listening sessions.

To prepare for the listening session, I started by looking at the minutes from the 2017 Annual Forum to look at what had issues had been addressed and what we needed to continue to discuss. Then, when I looked at the Board’s Annual Reports from previous years, I saw that the same list of concerns had been brought up year after year.

In 2019, we have a new OADS organization, led by a new Director, Paul Saucier. OADS is listening and have acknowledged that concerns previously generated in these annual forums are all important issues that need attention. OADS has already included many of them in their planning.

This year I wanted to get a slightly different perspective and ask the group whether the service delivery system of care for people with intellectual disabilities or Autism Spectrum Disorder is really living up to ideals refined over the years by the Developmental Disabilities Continuum of Care work group. The DD CoC was originally a parent and family advocacy group, but was joined by OADS and became a collaborative effort.

The prompts that follow represent the principles of an ideal service delivery system. What we wanted to explore in the listening sessions this year is whether these principles are accurate and complete and describe the system we want, or if they need to be revised. More importantly, does the system of care in Maine live up to these values? Do services line up the way we think they ought to? Where does our current system exhibit these characteristics, and where is it falling short?

See following pages for 2019/2020 meeting prompts.

Appendix C:

Public Feedback Forum
Conducted by the Maine Developmental Services Oversight and Advisory Board and the DHHS Office Of Aging And Disability Services

Monday, July 8, 2019
One Civic Center, Portland, Maine
With remote participation in Auburn, Orono,
Sanford, and Winthrop
12:00 Noon to 2:00 PM

See following pages for meeting minutes.

Public Feedback Forum
Monday, July 8, 2019
One Civic Center, Portland, ME
with remote viewing in
Auburn, Orono, Sanford, and Winthrop

2019 was the third year that 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. By utilizing the resources of the Coalition, the MDSOAB is able to 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.

In addition to the Portland meeting, the Board held hold two other public listening sessions this year, both of which were attended by Paul Saucier, the Director of the Office of Aging and Disability Services. The sessions were held in Bangor from 5:00-7:00 PM on Thursday, August 21st and in Lewiston from 5:00-7:00 PM on Thursday, September 28th.

Minutes from the Portland meeting
Monday, July 8, 2019

Cullen Ryan introduced himself and welcomed the group. Participants introduced themselves. 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.

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. 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 be a little different from MDSOAB annual forums in years past. Instead of a freeform discussion, there are a handful of identified prompts/principles on which the group will focus and comment. The DD CoC is being reworked to become a more linear presentation, featuring a series of one-pagers, and the group will be focusing on these principles as well. 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: Last year at this time, I had just taken my job a few months prior and was fairly new to the process. I started with the input from the 2017 Annual Forum to look at what had been addressed and what we needed to continue to discuss. The same list of concerns had been populated year after year. Paul Saucier, the new Director of OADS, has attended a number of these meetings as well as meetings of the MDSOAB – which is such a refreshing change from the previous administration. OADS is listening and they want to know our concerns, and they recognize that the list of concerns previously generated in these annual forums are all important issues that need attention and have already included them in their planning.

This year, I'd like to ask this group if the identified principles that were sent with the meeting materials, and slightly revised in the DD CoC meeting immediately before this, are accurate, complete, or if they need to be improved, revised, etc. More importantly, does the system of care in Maine live up to these values? And, do services line up the way we think they ought to? The system has to be adequately financed to address these needs. Where does our current system exhibit these characteristics, and where is it falling short? Both the MDSOAB and OADS would be very interested to hear your perspective. *(Click here for the Prompts for the 2019 MDSOAB/OADS Listening Sessions)* [Also included as Appendix E to this report.]

Forum Discussion: *The following bulleted list is the direct feedback generated from attendees, with any responses to questions/comments indented and identified by the speaker, as relevant.*

- More accountability across divisions within the Department, which is siloed. When there's an issue people tend to get sent to numerous different places within the Department with no one person or office taking accountability. Part of this is communication, but it's also about accountability.
- There should be more service providers across the state, so choice isn't limited across Maine's large geography.
- We can address the problems in a way that creates a better system for everyone. Working in Special Education, I saw that a lot of the effort was about improving the classroom environment for everyone. Communicating both that this is such a significant need, whatever that need might be for instance transportation, as well as possible ways of addressing it while thinking about having a more robust system for everyone.
- There isn't enough of a knowledge base in general. We're not teaching children and other people what it means for someone to have disabilities. To increase natural supports we need to educate people and reduce the fear and stigma around people with ID/DD.
- There's a lack of knowledge and educational materials for parents and consumers. We talk about choice, but we don't adequately educate people what those choices are and what it really means for people and their families to have their needs met.
- Providers need to work together. Providers all want what's best for people, but we tend to work in a very siloed way. Perhaps working across provider agencies would help with this.

- There is a distinct lack of choice for services, specifically for people who need one-on-one support, as well as day programs. The overall lack of capacity limits choice as well, including where people can live, etc.
- It's hard to say what would make transportation better until we know what it looks like when it's functional. All of us coming together to work on a couple big issues that we know are the Department's priority issues, so we can make progress, would help. Things tend to get pushed towards the bottom of the pile, so we need to really tackle that pile, and point out the very dysfunctional aspects of the system so that we can get some functionality.
- We see that the Section 21 waitlist has 1600 or so names on it, but that can be misleading. Every case manager gets everyone eligible for Section 21 services on the waitlist, and everyone is eligible for both Section 21 and 29. We have a misleading number of people who are currently in need of Section 21 agency home supports – one of the differentiators between Section 21 and Section 29. The Department finding a way to differentiate what those needs are and how many people are actually in need of Section 21 services, and being transparent about it, is important. How many people are on the Section 21 waitlist who are also not receiving Section 29 services – people who are receiving nothing right now except perhaps case management?

Emily Kalafarski: I believe that roughly 70% of the people on the Section 21 waitlist are receiving Section 29 – but I'll follow up on this.

- Maine hasn't been in compliance with many of the elements of Maine Statute Title 34b, which came about in preparation for the closing of the Consent Decree. One of those elements speaks to the importance of identifying unmet needs, who has them, how many, and in what categories. This is supposed to inform the budgeting process. Taking a fresh look at 34b would be advantageous.
- Communication from the Department has deteriorated in general over the years. There was a time when we knew more about what services were out there when we had a DHHS website that was user friendly and could be easily navigated. Also, the Department used to send emails with more regularity.
- One requirement which came from the Consent Decree was the Department maintaining a current resources directory, published every year. Providers used

to be able to list the services they offered, and have it published on the DHHS website. This has fallen by the wayside.

- The current system is extremely confusing for families.
- I have child who had to move out of the state and was finally able to come back to Maine. When I think lifespan, I think that I want to be able to die in peace and that my daughter's life won't come to a halt when I can no longer care for her. Families make ongoing efforts to see that their children can live as independently as possible. Moving from the family home into whatever residential option is chosen is better for everyone. Helping someone become more independent from childhood throughout the lifespan – it all comes down to money, having support available for the individual and family. My daughter lived a very rich life on paper – she did all of these activities which she loved, but they ended after she left that scheduled activity. What she really needed was peers; peer relationships are essential and is larger than what a family can do.
- The Blueprint for Effective Transition really contemplated personal relationships, which is one of those more elusive things to write on paper, yet is pivotal to someone leading a fulfilling life.
- Many people don't feel that the supports they receive are supporting the goal of independence. This is an essential goal about which everyone ought to care.
- As a provider I have seen that a lot of DSPs (direct support professionals) aren't truly independent – they live with their parents, they don't know how to cook meals, etc. Many DSPs aren't included as part of their own communities. How are they supposed to be able to foster independence and community inclusion when they don't have it themselves?
- There appears to be a real problem with lack of community awareness – for instance a DSP in Biddeford trying to navigate the Brunswick-area community.
- Social media has drastically changed the landscape for community inclusion; this is where social connections are made now. This is a barrier to community access because there's a stigma and fear of predatory behavior when it comes to people with ID/DD using social media.
- The workforce landscape is changing in general.
- There is a workforce crisis. There are people who want to work but lack a high school diploma or GED; this requirement has been a barrier to hiring very qualified people.

- As a former DSP, I was getting paid less than a cashier at Hannaford to do this very intense work, and at the same time I wasn't able to pay the bills. DSP pay needs to be commensurate with the work people are being asked to do.
- A resource directory for DSPs, with things that staff have found out in the community that are inclusive etc., would also be very helpful. DSPs want to do more but often don't know what to do out in the community; often times they're new to this too.
- Some states have gone with a standardized software system to document services. The ability to go in and look across a similar playing field at agencies and develop those quality outcomes and the ability to desk audit those does not exist in Maine. It may exist within case management, but as far as the other provision of services that's the first step – developing quality measures and finding a way to consistently review those.
- Years ago, OADS had created its Roadmap to Services, which was very helpful.
- There needs to be flexibility within the system as people grow and evolve – as service wants/needs ebb and flow.
- There's not enough outreach to the up-and-coming social workers while they're in school, before they enter the workforce – both on the part of the Department and providers. Perhaps creating partnerships between the schools, providers, and the Department.
- Every year you have to ask people about their choice of provider – it feels more like a false choice because people don't really know about other agencies and what they offer. It's one thing to tell someone they have a choice, but if they don't know what their options really are, it's not true choice. Additionally, if there is only one provider in your area is that choice? No, it's not. Building resource binders with the agencies, their missions, and the services offered for informed decision-making, so people don't "choose" what they're being given would greatly help. Some of this might depend upon the program and service type – people often tour day programs for instance, but this is probably a lot less common for residential programs.
- There are still issues with community case managers and how well they provide the service. This affects every aspect of service delivery for people.
- Choice unfortunately boils down to availability and capacity in within the system.
- Not being able to receive other services from the same agency at which their case manager works drastically affects a person's choice.

- There's a lack of clinicians who are specialized in this field, specifically communication consults.
- There's a need for more opportunities for staff training so that people can achieve their goals.
- Generally, families have a huge investment, knowledge base, and presence in the community. The system as it currently exists has a heavy reliance on parents and guardians subsidizing the state. There are also ways the system discourages this as well. When my son went through transition planning I didn't know what a group home was, what a waiver was, etc., but I knew my son, I knew what he needed for modes of support, and could share that with someone if someone would have listened.
- : I think this is what is meant in the partnership and lifespan principles. If natural supports were extended in a partnership with formal supports it might produce better outcomes, as you could weave that into the lifespan.
- Being nationally connected (ANCOR – American Network of Community Options and Resources), these types of conversations are happening in every state across the country. There are some leading practices in other states around certain topics. If we could develop a way to have some of these leading practice ideas it would be helpful.
- : Perhaps ANCOR would be able to disseminate some of these leading practices at a future Coalition meeting through one or more of its members.
- Age-friendly communities are disability-friendly communities – there is an immense overlap between the issues, barriers, and needs of these populations, and there are ways in which we can work together for a mutually beneficial partnership.
- Person-centered planning (PCP) meetings are not person-centered, it's a checklist for the case managers. Even when people have goals they're not being followed through.
- Prevention is also important and is largely overlooked.

Mark: We're going to try to do two more of these listening sessions – one in August in the Bangor area in the evening at OHI, and one in September in the Lewiston area.
Cullen: If you have any additional feedback please attend one of the upcoming forums or reach out to Mark directly via email: kemmerle.mdsoab@gmail.com.
Mark: Also, regarding community inclusion, the Home and Community-Based Services

(HCBS) Settings Rule will tell us pretty definitively what community inclusion is, if we’re meeting it, and provide guidance on how we can get there.

Cullen: Mark, thank you for being here. This generated a great discussion!

End Presentation *(round of applause)*

Appendix D:

Public Feedback Forum
Conducted by the Maine Developmental Services Oversight and Advisory Board and the DHHS Office Of Aging And Disability Services

Wednesday, August 21, 2019
At the offices of OHI
203 Maine Avenue, Bangor, Maine
5:00 PM to 7:00 PM

See following pages for notes and transcript.

Public Feedback Forum
Conducted by the Maine Developmental Services Oversight and Advisory Board and the DHHS Office Of Aging And Disability Services

Wednesday, August 21, 2019
203 Maine Avenue, Bangor, Maine
5:00 PM to 7:00 PM

GENERAL:

Approximately 85 people attended this two-hour forum. The venue was able to provide Zoom capability, including recording of the proceedings as well as a hand held microphone to support the speakers. Unfortunately, this was the first time that ZOOM was used at this location and the recording was inadequate. The participants consisted primarily of family members and people who receive services. Also present were representatives of provider agencies, including Direct Support Professionals, Disability Rights Maine, the University of Maine, two OADS consultants and the Operations Manager of OADS present.

This Listening Session was hosted by OHI. Primary listeners for the OAB and OADS were Mark Kemmerle, Executive Director of the OAB and Paul Saucier, Director of OADS. Mr. Kemmerle reviewed the News Flash that the OAB had provided to the attendees that included Propositions focusing on how well the current system of care serves Maine citizens with intellectual and developmental disabilities or autism spectrum disorder and how well it embodies certain principles. Mr. Saucier made it clear that they were both there to listen and to take feedback to the Department that is in various stages of developing its prioritized Work Plan based on the identified System needs.

Following, were major themes that emerged during this Forum:

1. **Unmet needs of parents and their children with autism**
    a. Lack of knowledge of services that are available
    b. Lack of seamless transition from children's to adult services
    c. Lack of adequate and timely diagnosis, particularly related to autism spectrum disorder
    d. Inadequate resources at Eastern Maine Community College to accommodate students with autism
    e. Difficulty for children with autism developing avenues to find friends
    f. Single parents trying to cope with raising a child with autism with challenging behaviors and trying to work and support a family

   g. Difficulty for parents in getting to meetings to network with other families and to learn more about services that are available
   h. One parent said “no one cares about people with autism”!
   i. Another parent said “people just don’t care”.
   j. “Kids need programs” to meet their needs.

2. **Waiting Lists**
   a. Several people spoke of the waiting lists for Section 21 and Section 29 services. Several examples were provided.
   b. One parent stated “all people should get the services they need”.
   c. Another parent worried that she was fearful she would die before her adult person receives services.
   d. Others talked about the stressors and the toll on the family unit.

3. **Communication**
   a. There are challenges with identifying what services are available for people with intellectual disabilities and their family members.
   b. Many families don’t know how to find out where to get help. How does a person get public information?
   c. Lack of responsiveness from professionals and from OMS to telephone calls of inquiry
   d. Parents need more information about available “public benefits”.
   e. Case Managers are often not given enough information to adequately answer questions and their explanations are often “difficult to process” – perhaps, because they don’t fully understand the system or the issue.
   f. “I don’t know what supports my daughter will get when she turns 18!”
   g. What is meant by “choice and flexibility”?
   h. The local DHHS office does not know the answer to questions. Others said they don’t know who to talk with the local DHHS office.
   i. There needs to be more opportunities for parent and family networking.

4. **Personnel**
   a. There is excessive turnover of Direct Support Professionals which creates inconsistency, injuries to both staff and people receiving services
   b. There is a failure of agencies to meet hours of support recommended by the Person Centered Plan due to lack of staff
   c. There is a lack of adequate pay, benefits, and quality and quantity training for Direct Support Professionals, particularly for those who are supporting people with complex needs, including dual diagnoses and medical conditions
   d. There are workforce shortages which cause Direct Support Professionals supervisors to spend significant part of their day in filling vacancies doing direct support.
   e. Society does not pay staff enough so they’ll stay.
   f. There is an inadequate number of staff to assist people to access and be fully included in their communities

g. There was a question about how Maine can reach compliance with the Community Settings Rule when there is lack of staff to support people to be fully included in their community.
h. There were concerns that Direct Support Professionals doing complex work under difficult circumstances with vulnerable people are not paid a “living wage”.
i. The process of obtaining or changing services is “very convoluted and complicated”. Concerns were raised that there is a “dearth” of personnel to process HCBS Waiver Applications.
j. DSP’s are expected to be professionals. Several mentioned that it is necessary to professionalize the workforce and this is impossible to do when the rate does not accommodate hourly wages competitive with Walmart Greeters, McDonalds and retail establishments.
k. Some said that it is impossible to assist people to reach their goals when there is inconsistent staffing and the turnover is getting worse.
l. “The real value in what we do is seeing someone’s life getting better”. This is difficult to accomplish with the staffing crisis.
m. BHP’s and Clinicians do not get paid enough so there are serious recruitment and retention challenges.
n. Several mentioned their thanks to “agencies who work so hard”.
o. One person mentioned that there is “uneven quality in the workforce”. There needs to be more effective quality training.
p. Some believe that the workforce crisis is tied to Maine’s low unemployment rate.
q. One person who receives Personal Support Waiver services said that she does not receive all of the hours that are approved because the agency can’t find enough staff to work. She said she wants MORE hours not LESS hours.

5. **System Redesign and Issues**
    a. There were questions about self-directed services. What does this mean? Can Maine offer these services? Why isn’t Maine offering these services? Who would be eligible?
    b. There needs to be more community inclusion.
    c. There was a request that there be more “exciting” and “higher quality” services available for people [esp., community activities for higher functioning adults]
    d. There needs to be system changes that will result in not so many people “sitting home.
    e. People need to be exposed to options for services
    f. Some said that too much money goes into “narrowly focused programs”.
    g. Rates are going down but costs are increasing!
    h. There was praise for the availability of the Katie Beckett Waiver.
    i. There must be system redesign that assures that kids don’t grow up and “slip through the cracks”.

- j. There needs to be seamless continuity of services when a person turns 18.
- k. It was recommended that the state be transparent in sharing waiting list numbers, in sharing data about the service delivery system, and in stating what the true unmet needs are.
- l. Transportation is an issue.
- m. There is a lack of access to appropriate and adequate services and resources for people with complex needs. What is the data about who has received these services and who has not? Who has lingered in the emergency rooms or been sent out of state because of lack of resources?
- n. Some believe that emergency rooms are not designed to hold people for days when there is not a place in the community for them to go and/or the availability of a psychiatric in-patient bed.
- o. Addressing the loneliness and isolation that some people with disabilities feel is as important as other things! “Friends are the treasures of a happy life”!
- p. Lack of adequate number of vehicles to transport people to community opportunities was brought up several times.

6. <u>Other</u>

- a. A Model to be looked at by Maine is being used in Florida very successfully. It is known as “Natural Links for Lifelong Learning”, suggested one person.
- b. Child Development Services (CDS) is not supportive and the turnover in CDS is high. One parent mentioned “going down” to CDS to get answers when she could get them over the phone and still not being able to talk to anyone to get answers.
- c. The PEERS Program at the University of Maine was discussed. It was recommended that there be more available information about this program.
- d. Concerns were raised about the failure of some school districts to comply with the federal law (IDEA) in providing special education services. One parent mentioned the school did not follow her son’s IEP and the parent ended up paying for Occupational Therapy. She said that she was financially able to do it but most parents are able to do so and their children should expect the school and state to be in compliance with federal law.
- e. One guardian shared the story of her 2 nephews – both of whom ended up in the local emergency room – one ultimately sent out of state at a much higher cost than he could have been managed in Maine. The other nephew ended up there because of lack of approval of the resources needed to environmentally engineer his space and to live in a home by himself. She recommended that DHHS meet with all Maine E.R. departments and evaluate their ability to serve complex persons with disabilities.

f. “Children’s and Adult service are separate animals” [and shouldn’t be. Better coordination is needed. Each group needs to know more about services provided by the other.]!
g. There was discussion about E.V.V. One person said she was “scared to death” about E.V.V. and also said she believes that this requirement, in some aspects, is in violation of the Olmstead Supreme Court case.
h. One mother described the national “START” program at the University of New Hampshire and recommended that Maine look into this program.

In Closing: There were several people who expressed their appreciation to OADS and OAB for holding this Listening Session. They were thankful that someone was listening to them. Mr. Saucier and Mr. Kemmerle thanked the listeners for their thoughtful comments and recommendations. They made it clear that there are many issues and many of them are complex and will take resources, collaboration and innovation to solve. At this time, they are learning and developing a strategy for resolving as many issues as possible.

Respectfully submitted:

Bonnie-Jean Brooks – OAB Member and CEO of OHI

Additional notes prepared by Craig Patterson, Operations Director, OADS:

MDSOAB and OADS Listening Session – Bangor
OHI Offices, 203 Maine Ave, Bangor
Wed, August 21, 2019 (5:00-7:00 PM)

Mark Kemmerle began the evening's listening session by introducing himself as the Executive Director for The Maine Developmental Services Oversight and Advisory Board. Mr. Kemmerle provided a brief background regarding the MDSOAB history and then outlined how the Board works to advocate for services, sharing many of the same values and principles that Maine's Office of Aging and Disability Services have set as important standards in delivering care to the individuals they serve and their families. These include; a continuum of supports through the lifespan, supports for families, safety, inclusion, person-centered approaches, choice, independence, flexibility, coordinated access and quality outcomes. Mr.Kemmerle then remarked briefly on what he described as "positive change" within the service system and commented that from his perspective the willingness to engage and partner with providers, communities and the people served was no longer lacking as it had been for the past several years under different leadership. Mr. Kemmerle then introduced Maine Office of Aging and Disability Services Director, Paul Saucier and Disability Services Operations Manager, Craig Patterson.

Director Saucier then provided brief comments acknowledging that OADS has a "lot of work to do" and that it could not all be done at once. He went on to say that OADS needed help in identifying issues within the system and that those in the audience could assist by sharing as much as possible. Mark Kemmerle then opened the session for comments which follow.

Eric McVay (Bangor) – "I'm from Bangor and I've been on the waiting list for Section 20 for a year and a half. When is the Legislature going to act? We need to move to get everyone off of all waitlists." Mr. McVay then turned to Director Saucier and asked "Can you work with the Legislature to make this happen?"

Maggie Hoffman – "I'm grateful you're here. My son is on the section 29 waiver and on a waitlist. In 2019 the Legislature and state Government decided only some people are eligible for services. Services should be available to all with no waitlists. Services should not be just community placed, they need to actually be part of the community. We came from a place that I refer to as "fantasy services" – self directed. How do you assure quality of services? I think self-direction only works with real community. Some folks have multiple conditions. I heard someone had to move because he did not get along with staff, it was his home. Staff need livable wages and better training to address complex needs.”

Greg Bush – “I have put programs in place in other states. Building friendships is important. There need to be better programs that are exciting and available in rural areas. A lot of people are not sure what it is that they want to do. A lot of funding goes into work programs that are narrowly focused. LD 852 passed unanimously – parents need better public benefits knowledge.”

Cheryl Halberson – “I have a 19 year old autistic son (recently diagnosed). His case manager put in an application a couple of months ago. I’ve heard there is one person to process all applications. We are left on our own. My own illness is getting worse and our Case Manager comes to help but what he says is hard to understand.”

Roxy H. – “I’m in a good group home, but there is not enough driving. We need transportation.”

Julie Helwig – “Where do supports come from? Direct Support Professionals (professional is an important term). D.S.P.’s get paid the same as Walmart, McDonalds employees. The College of Direct Support is not supportive to potential staff. The turnover rate is incredibly high. We can help people to reach goals if supports are consistent. People served are always on edge. D.S.P.’s are seriously underpaid. How many times has minimum wage gone up yet D.S.P.’s pay has stayed the same. If people can make a living, they will come for these jobs.”

Kathy Lyons – “I’m the parent of a daughter diagnosed at age 13 with high functioning autism. A lot of parents live alone and it’s extremely difficult. My girl is going through gender identification issues. Her life became more difficult. She now gets Katie Beckett services and that has helped. We got a Case Manager Receiving HCT services is like “hello we’re here, goodbye we’re gone”. My primary concerns are; improving how the public learns about services (is there a clearing house for information?), partnership (we have 3 Therapists, 2 social work counselors), lifespan (need more information), we’ve been waiting on Section 28 for a year and a half, a lot of kids are slipping through the cracks, HCT is helpful, privacy issues are a block, choice/flexibility (what kind of choice do parents actually have?), B.H.P.’s go away too quickly, there is a huge staffing turnover (it’s a difficult job).

Unidentified - “I work for an agency but what I hear from these moms is that there is no continuity of services.”

Eric McVay (Bangor) – “The Section 20 waitlist is bad. The Department and the Legislature need to work together to end waitlists. It’s a broken system. It needs to be fixed. It’s gonna take some time.”

Unidentified – “I’m a parent of an autistic son who is 22. How do I find information on sections 20 and 21?”

Unidentified – "I'm a home manager. DSP's are not paid enough. Staff can't even get their own transportation issues resolved on what they make. I'm also a little bit worried about EVV (Electronic Visit Verification). We've spent money already. The verification system will take staff away from the people served."

Unidentified – "I have eight (8) hours of staffing. I need more support. I may have to leave my apartment if I can't get enough support. I don't want to live with my mother for the rest of my life. I don't want to lose my independence. [Provider name redaacted] has done badly but OHI is better. Without supports I'll be living with my mother for the rest of my life."

Margaret Longsworth – "I'm Co-guardian for two nephews. Right service at the right time? Hmmm. I estimate that one of my nephews has cost the state two million dollars. He spent 32 days at EMMC. The Department should assess E.R.'s across the state. The APS requirement for [eligibility for] section 21 [services] is a horrible concept."

Unidentified – "I have an autistic son, but I didn't qualify for MaineCare. The School system failed. We couldn't get a Case Manager. He graduated second in his class and goes to college at EMCC. He has no friends. There are no programs. The School system doesn't care. Nobody cares about autism. It's been a nightmare. The school never followed the I.E.P. Staff are underpaid – who would do that job for that pay. My son can't get a job. He has college issues and no supports. It's torture for kids in schools with no supports. I don't know what lies ahead."

Alan Cobo-Lewis – "I have a list of concerns I'd like to share. 1) The waitlists are a problem. There seems to be 1500 people on 21 and 250 on 29. Sections 20 and 18 have a couple dozen on waitlists as well. 2) In regards to a person being evicted from a house because they couldn't get along with staff – services need to be separated from landlord role. 3) We need transparent data sharing for waitlists, unmet needs and expenditures for services. 4) Workforce – Staff need to be adequately paid. 5) A [individual] DSP may be bad but there is uneven quality of staff. There needs to be appropriate training. These problems are not caused by economic issues alone, Reimbursement to providers should be connected to quality. 6) Transportation issues are huge and need to be addressed."

Unidentified – "Variability of need – When my son went into crisis, the system could not respond effectively. Staying on hold with agencies for 90 minutes doesn't work. The Legislature must take action on staff wages. The lack of access to services because of complex needs. Agencies can't provide – who's being served or underserved because of complex needs?"

Judy St.Clair – "There are not enough staff to get out often."

Unidentified – "I'm a parent of a son with autism. We moved to Maine seven (7) years ago from Oregon where we had no services. Emergency Rooms were never designed to care for those staying for long periods to accommodate complex needs. Autism is different than M.R. or Down Syndrome. How can we work together to do things like L.D. 852? How can we improve the system? I encourage all here today to get involved with the Legislature. The public doesn't know; doctors don't know. We need to educate them ourselves."

Bonnie Robertson – "I'm the parent of a 40 year old with developmental disability. I understand the shortage of staff and lack of pay. My son suffered serious sun burn because staff (backup) didn't know he was vulnerable. He was also injured once in an incident involving the car door."

Unidentified – "I just want to make a shout out to the parents here. I urge you to reach out to the Maine Parent Foundation."

Unidentified – "The continuum of care is horrible. Children's agencies don't know the adult system. I'm afraid of EVV. It seems like this is an Olmstead violation. It shouldn't apply to D.D."

Unidentified – "Our priorities are different. At quarterly provider meetings in Bangor, providers don't know anything and DSP's need more."

Unidentified – "The START Program in New Hampshire works well. Staff are trained well."

Janet Hamell – "I'm a parent. With transition plan, addressing loneliness is as important as anything. The State Transition Plan should allow for all types of residential programs. Meaningful relationships are important. Funding is important but doesn't resolve all issues. We received Section 21 services for twelve years. We left for 15 years and have come back. My daughter is now on 2 waitlists. If we are not going to have institutions, people need support."

[Senator] Geoff Gratwick – "I'm a legislator and I want to say to everyone, please vote. Make your voices heard."

Janet - "I want to echo that. Please help people learn how to vote."

Roxy H. – "We need more staffing and more vehicles."

Paul Saucier (OADS Director) – "I want to thank you all. It's impressive to see the size of the crowd, to hear the concerns, the positive solutions, the respect you've treated us with. I want to summarize some of what we've heard you all say tonight. We've heard concerns regarding; 1) transportation, 2) residents with complex needs, 3) workforce issues including pay and training, 4) the need for more quality programs, 5) access to information regarding services, 6) poor services for autism, 7) The need for more networking, and 8) the continuity of care. Thank you again."

Appendix E:

Public Feedback Forum
Conducted by the Maine Developmental Services Oversight and Advisory Board and the DHHS Office Of Aging And Disability Services

Thursday, September 26, 2019
At the offices of Community Concepts
240 Bates Street, Lewiston, Maine
5:00 PM to 7:00 PM

See following pages for complete transcript.

STATE OF MAINE
DEVELOPMENTAL SERVICES OVERSIGHT AND ADVISORY BOARD

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IN RE: PUBLIC MEETING CONCERNING SERVICES PROVIDED TO THOSE WITH INTELLECTUAL DISABILITIES OR AUTISM BY THE DHHS OFFICE OF AGING AND DISABILITY SERVICES

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Taken before Debra J. Fusco, a Notary Public in and for the State of Maine, at Community Concepts, 240 Bates Street, Lewiston, Maine on September 26, 2019, beginning at 5:04 p.m., pursuant to notice given.

*** PROCEEDINGS ***

MR. KEMMERLE: My name is Mark Kemmerle. I'm the executive director of the oversight and advisory board, the MDSOAB, which was created by the legislature in the wake of the settling of the consent decree that closed Pineland. And when Maine went from institutional care to home- and community-based care, one of the safeguards that the legislature provided was a group of volunteers, there were 15 on the board, and its job is oversight and advice. So I've been involved with the board for about three years. I have a 33-year-old autistic son, and I was a participant on the board before I became executive director. And the last several years were very difficult and it was a struggle dealing with the aging and disability services. But since the new administration, it's been quite a turnaround and we've gotten -- I would say we actually have a relationship with the department. And if we advise, you know, it's not resented or, you know, who are you or what do you think you are? But they've been receptive and we're very optimistic about the next seven years. That shows you how optimistic we are.

I started about a year and a half ago, and one of the first things I had to do was to write an annual report for the board to the legislature, and what I started with was the notes from this session two years ago, and then I found notes from other sessions in previous years. For the last few years, we've only been holding one meeting, and it was in conjunction with the Maine Coalition for Housing & Quality Services and they meet once a month, 10 a.m. to 2 p.m., but they have 14 cites around the state that you can watch. You can go to one of the cites and they have zoom and they're telecast, interactive. So that was the best way for us to meet, reach out to as many people as we could at one time. But it wasn't ideal because, you know, 10 a.m. to noon, people work. So this year OADS said, let's try to go out, go to different places, let's have them in the evenings, let's have them on a day other than Tuesday. So we've done three this year, one in Portland with the coalition, one last month in Bangor and now one in Lewiston. And, you know, next year maybe we'll go to Calais or Dover-Foxcroft or someplace and try to get deeper into the state.

But when I looked at the transcripts -- I'm digressing. When I looked at the transcripts of the past meetings, I was sort of surprised and taken aback that the concerns of families and residents, they were pretty much the same from one year to the next. It was a little disheartening to see the same problems year after year being voiced at these meetings but that's also useful. So this year, I wanted to take a bit of a different take so that we didn't get a transcript that looked exactly like last years and the years before. But I still -- the department and the board, we want to hear what your concerns are. But I was trying to sort of shape it. And we had been working with a document in the coalition called the continuum of care and it was jointly developed with the department and with parents, our parent group. And if you saw the flyers, it was sort of the principals on which a system of care ought to exhibit: Self-determination, flexibility, choice. What else did we say --

MR. PATTERSON: Services through the lifespan --

MR. KEMMERLE: Services through the lifespan, childhood to adult. Because one of the things that I'm sure we're gonna hear tonight is this thing that happens when you leave the child services world and enter the adult services world. Everybody acknowledges that it's an extremely awkward transition and it needs to be addressed. You can tell us that. You don't have to forebear just because -- I'm not trying to say don't tell us about it just because we know it's a problem.

It's about you. And so really it's -- what we heard at these meetings went into our annual report to the legislature. We could say here's what the citizens of Maine think about the services that are being provided by DHHS and others, and here are our recommendations, here are -- you know, that we glean from the citizens, residents, everybody who provided input. And so that's what we're here to do is essentially to listen. And it's your meeting, you have the floor. Paul, Craig and I will listen, Debbie will provide us a record so we can go over it when we get home.

So, Paul, would you --

MR. SAUCIER: Yeah, just to thank the OAB for sponsoring the meeting. We're very happy to join them in these meetings this year. As Mark said -- I've been in the job about six months, and there essentially was no relationship with the OAB or any other stakeholder groups of significance when I came on, and I'm happy to say that that has changed. We have good working relationships now with many groups, provider groups, advocates, family groups and want to continue to deepen that because I believe we can only improve the quality of services by getting feedback and hearing from all of you so that's very much why I'm here. I'm really glad that you all came out on a rainy night. I

appreciate that very much. I found a system that has got some pretty serious challenges. I won't bias you because I want to hear what your perception of the system is, but there were some immediate short term things that we had to start working on right away. And then we've been engaged in several stakeholder processes to kind of put together and prioritize a list of other things that we need to work on going forward. So I'm really looking forward to hearing what you all have to say this evening. And since we are so small a group, can we do a round of introductions?

Would that be alright?

MR. KEMMERLE: Yeah, that's fine.

THE WITNESS: My name is Bob Carpenter. I live in Union, Maine which is by Rockland. I moved to Maine five years ago by choice. You know, Bill LePage was here. You know, I should have gone to another state because he doesn't want to spend money on me because of my daughter. I have a 30-year-old daughter with autism.

MR. SAUCIER: Let's just continue around, just get people's names and why they're here, and then we'd love to hear more about your story.

MR. CARPENTER: Okay.

MR. GOODWIN: Hi, good evening. My name is Todd Goodwin, and I'm the incoming CEO for John F.

Murphy Homes which is a provider of a broad range of services based in Auburn. I appreciate the opportunity to be here, and I have a couple of concerns that I would like to share and, you know, participating in working to improve the system so thank you for putting this together.

MS. BENTLEY: I'm Ann Bentley from John Murphy Homes as well, and I am a long-term employee there. And I'm also here because I have seen over the past 30 years some services that I think we haven't -- we have lost and I would like to see those reinstated.

MS. CRAVEN: I'm Margaret Craven and I represent part of Lewiston and the Maine State Legislature, and I serve on Health and Human Services Committee and represent a lot of constituents that have a lot of concerns about services for their loved ones. And way before I was at --

MR. KEMMERLE: That's right.

MS. CRAVEN: And thank you for your service.

MR. McKENNA: I'm Steven McKenna. I'm a father of two autistic adult men, 21 and 23 year olds. They both have moderate intellectual disability and autism, and they're in desperate need of services and the system has been fighting us.

MS. MURPHY: Hi, I'm Sue Murphy from

Spurwink, and we have adult services in York, Cumberland and Androscoggin County and I've also been in the system for a long time and I'm very interested in hearing what the concerns are of family members and concerned people.

MS. SCHNEIDER: I'm Linda Schneider and I have laryngitis. I've been a provider for a very, very long time. And I'm currently working with a small mental health agency to develop adult foster homes for people with autism. And my first husband had Aspergers, or what was called Aspergers. He was a yalely but, you know, he was in his 50s before he was diagnosed so I had an interesting marriage for a very long time. So it's something that is near and dear to my heart.

MR. WAGONER: My name is Larry Wagoner, I'm from Independence Association. We're based in Brunswick, Maine but we serve the surrounding area and our chief executive Ray Nagel is going to be here soon. We serve people with autism and intellectual disabilities.

MS. MUJICA: I'm Virginia Mujica, owner and executive director of Infinite Potential adult habilitation services, we're a small agency in Casco and we service intellectual disabilities but primarily high functioning autism, Aspergers.

MS. HAGAR: My name is Dawn Hagar, I'm the office manager at Infinite Potential.

MS. WESEL: I'm Lisa Wesel, I live in Bowdoinham, and I'm the mother of an adult daughter with a rare genetic disorder that she has intellectual disabilities and seizures and she receives -- she's 23 and she receives Section 29 which is enormously helpful and I'm very grateful to the state for expanding Section 29 so she has full access to services. But she is on the interminable wait list for Section 21 which is a huge concern to me and my husband because the question that lingers forever is what will happen to her when we're not here, and that is an obsessive force in our life, to figure out what the answer to that question is.

MS. HUMPHREY: I'm Kim Humphrey, and I have a 30-year-old son with severe autism and bipolar characteristics that lives here in a home with another man with autism supported by DSPs and with -- it's a well-run group home which I'm grateful for. I'm also founder of a family advocacy network to connect families, caregivers and communities to support raising the standard of care for people with developmental disabilities, and I'm a regular participant on the oversight advisory board.

MR. ESTABROOK: My name is Richard Estabrook. I'm on the board of Independence Association. I'm not speaking for the board, I'm only speaking for myself, and I live in Brunswick, Maine. Thank you.

MR. SAUCIER: So who would like to start?

MS. CRAVEN: So one of the concerns that I hear constantly is a shortage of staff and for the reimbursement to be so low that providers can't afford to hire staff, and that programs are actually closing in this section, in this district at any rate, because that providers can't compete with Wal-Mart or McDonalds or those kinds of places who have very little responsibility, their staff has very little responsibility compared to the skills and responsibility that's required when one is caring for people with disabilities. And so I have a bill that was not funded, it was passed but not funded, that would -- the number of the bill is LD399. It was carried over. And certainly it would help if that bill -- if that bill was funded because it would provide funding for staff all over the State of Maine.

The other two big concerns I have is the waiting list and for Section 21 and Section 29 because the Section 29 has been growing as well now all through this year. And the waiting list, which is another thing, there's 1,600 people on there and the configuration of the waiting list. So my good friend Jane Gallivan, of the old days, configured the list which means that people that are designated in the No. 1 section are the only people that will ever get placed anywhere. So everybody else in the entire waiting list will never go anywhere. It's ridiculous because like people who aren't -- have a very, very high and expensive need just don't get placed at all. And, you know, there's not always use -- an open space for somebody with very high needs. If they're dangerous or if they can't be placed with somebody else where openings exist that can take people who have lesser behavioral needs or lesser of that kind of need. And so I really feel -- I'm really thinking next year of filing a bill unless somebody else takes a look at redefining the waiting list. So some of those people on the two and three sections have payrolls that are 90 years old and they're still waiting and their child maybe has Down syndrome or something so they're considered not at high risk.

I forget what the second piece was, but I'm sure it will come to me. So thank you. And I think that this -- this is not just coming from me. This is coming from Independence associates, John F. Murphy Homes, anybody else that I talk to and including parents that are waiting for Section 99 because they have access to us and, you know, it's a very big concern and I -- you know, and it's an emergency. If people that have a lot of those disabilities don't get placement and don't have somebody to mind them, it's not like they can wait a day or two days or three weeks or whatever. They have to have services now. So -- thank you.

MR. SAUCIER: Thank you.

MR. GOODWIN: John Goodwin, John F. Murphy Homes. I'd like to perhaps latch on to or add to what Margaret said and this is -- we're not tag teaming or anything, we're independent participants here. But I appreciate the comments that I heard back here about parents who are concerned with this long wait list. You know, I -- again, I appreciate the fact that we're having this conversation, and I think we need to have more of them. But I would like to address this -- some funding issues with respect to Section 21 and group home services. And, you know, I'm gonna be repeating things that many people in this room have talked about and heard for years. Several years ago when I was with -- I was the president of the Maine Association for Community Service Providers and a coalition, a collection of providers of services. And years ago we were talking about the growing crisis with respect to Section 21 group home services and it had to do with exactly what Margaret is talking about, namely a funding mechanism, a funding model, a funding system that does not and has not recognized the costs for doing -- for providing that service in a group setting.

I'd like to acknowledge that through legislative efforts a couple years ago and, you know, the cooperation of the department, I would like to acknowledge that providers of Section 21 services have indeed seen an increase in the rates for those services. However, at the risk of sounding like a provider -- at the risk of reinforcing a common mantra that occurred under the previous administration, at the risk of sounding like someone who -- a provider who is just begging for money, I think it's important to recognize that it is indeed still a crisis. For years again we've been talking about rates and then along the way our state passed, as everyone knows, a minimum wage law. The increases in rates that we have seen over the last couple of years do not recognize the minimum wage and the ongoing increase in minimum wage. I often hear and have heard for years that the wait list is growing in large part either because provider organizations are cherry picking people on the wait list or there aren't enough providers. Both of those impressions are wrong, and they're not based in fact, they're not based in reality. The wait list is growing because the rate structure and the funding model has not kept pace not only with the minimum wage but the increase in cost of providing the service and running an organization that has the mechanisms and the structures in place to ensure a good quality compliant service.

I would be more than happy to -- I mean many providers -- there are other providers that can probably speak more eloquently than me about it, but Paul or Craig or anybody -- and you may already have such documents, but I think any number of us could provide you a very detailed financial schedule that really breaks down the rate for the Section 21 service and how that gets deployed across an organizational setting, okay? I'm not -- I have one here. I would be happy to provide more, and I certainly am not going to walk through this in any great detail, but I did want to point out just one thing, just one thing. Right now the rate for the service has -- as many know is 27.71 per authorized hour, right? Now, when you apply that to an organization that's employing a highly trained, highly regulated direct support professional, there are costs that go with that, okay? So as an organization, as we start applying the costs of employing DSPs running homes -- which, as an aside, I think it's worth noting, there's no room and board reimbursement, we know that. Take that out of the mix for a moment. By the time we start accounting for FICA and federal and payroll -- all the payroll taxes, administrative overhead, training, overhead as a result of the workforce -- excuse me, over time as a result of all of the workforce challenges, what we come down to is a wage -- and these figures, I think, are pretty standard. I'm looking at John F. Murphy Home figures. These are not unreasonable figures. The wage portion of the rate for direct support professional is $11.22 an hour. The minimum wage is gonna go up to $12 an hour January 1st. Margaret talks and others talk about competing for employees. This is an incredibly real phenomenon. I do not see the wait list -- any progress being made on the wait list without some serious attention, again, ongoing to the rate structure. It has to be indexed to the -- at minimum it needs to be indexed to minimum wage. I think there's a lot more that should be done. John F. Murphy Homes, and I would defer to Ann here, she has a longer tenure than I. I certainly know that we have group homes that stand empty. We are not taking people off the wait list. It's not because we don't want to. John F. Murphy Homes has a long history in this community of serving people and developing programs, oftentimes very specific individualized programs for people. We have group homes standing empty because we're not accepting people because we don't have the staff, and we don't have the staff because we can't pay the staff.

So, again, thank you for the form. I know it is a big challenge. Paul, I appreciate your comments about significant challenges. You're exactly right, there are. But we're gonna keep talking about this rate issue, particularly for the Section 21 service. Something has to be done. Group homes are closing, as Margaret said. We have them. They will continue to close. It's an economic fact.

So thank you. I appreciate the opportunity to offer some comments.

MR. SAUCIER: Thanks, Todd.

MR. McKENNA: Steve McKenna, a father from Shapleigh, Maine. And I'd like to tag on what they both just said about the wait list, and specifically the word "crisis". Because the current system, if you do a simple Google search about the constitutionality of a wait list, it has been defeated in many states for this exact reason. Because the only people that are getting served are in crisis, and what's happened is our system has pushed everybody into crisis. It's even pushing the community case managers to push for more documentation to push these clients into a crisis even if it's not actually a crisis but on paper it's a crisis. And what it's doing is it's portraying these individuals in a more negative light that they require more support than they do so that they can get funding to get the support that they actually need. And when the 29 waiver comes through, that's great. My boys got their 29 waiver, we didn't have to wait. I see in May that we had 160 some odd people on a wait list now for that. And at the bottom of that notice it said, these are some of the steps the department is taking to make services more accessible and better. What? What? We added 160 something people to another wait list and that's a step to make services more accessible?

MR. CARPENTER: I'd like to comment.

MR. McKENNA: When my son was diagnosed over 21 years ago, he was less than two years old. And at that point in time, they told us that it was like one in 10 or 20,000 people were diagnosed with autism. We all see it in the news. Today it's one in 59 is the latest I've seen. This lack of resources, lack of staffing, lack of programs I think is compounded by the fact that there is an explosion coming of autism.

When my boys were diagnosed in the 90s, there was a lot of the vaccine questions and issues, there was a lot of autism being exposed, being diagnosed and it's only gonna get worse. The system needs to -- look, this outline -- and, Mark, thank you the other day for speaking with me on vacation. In concept, this is great, right? In concept this is great. The problem is that it's not being implemented in a line with the concept.

I made some notes. I went down through these points and just made some quick notes. The very first thing on this continuum of care is about partnership and it talks about how it's supposed to be a partnership between the individual, the family, the community and the government. The current system is not a partnership. Partners work together and are not adversarial. If the department would partner with families that support these individuals, it would be both more cost effective and result in more positive results for these individuals. Community case managers should support clients without OADS interference. The OADS liaison has become CCM and service providers Google of regulations. These private entities should not be asking the authorizing entity what they can and cannot submit for authorizations and this is what is happening.

And they call their liaison and they call their liaison and the result is we have CCMs who are less familiar with the regulations so they don't even know what services are available so we're having a lower quality of case management.

Let's move on to life span.

MR. KEMMERLE: Steve, do you think they're getting misinformation from the department or they're getting steered towards certain solutions?

MR. McKENNA: I think some of it goes back to what Todd was talking about, right, with pay rate and with jobs and we -- I know we've seen it in the news just over the last couple of years with the child protective services system and those case managers not being paid sufficiently for the stress in the jobs that they're doing. But I also think that is a big issue is that the community case managers are being pushed into this best practices model of monthly visits which is limiting their caseloads and robbing funds from services and service providers. And if it was truly targeted case management and you had somebody that was in a -- you know, in a supportive environment where they were receiving services they were happy and content with, they don't need monthly visits from a case manager. And they probably don't want them, but they're receiving

them and they're getting billed for them. These same individuals, like my sons, their MaineCare is being billed for a 90-day review assessment of the BMS99 that's not necessary. There are no changes whatsoever, but the case managers log into EIS and do a 90-day review and cla-clink, bill, there's another hour and it's stealing funds from the service provisions, it's stealing potential fund rate increases to the service provisions, potential expansion of services that could be available by this best practices. It's kind of like the entire population is being penalized because a couple case managers in the state made some very, very serious mistakes. And what's happened is it's cost the system and it's costing all of the clients and the MaineCare members services is the result downstream.

Let me move on to life span. We were told at age two when Gavin was diagnosed, early intervention is crucial. The same holds true for adults. By putting these people onto a wait list and pushing them into a crisis, we are driving the cost up. We are kicking the can down the road and when we get there, it is wicked expensive. If we funded the services that they needed immediately, they would be better off two or five years down the road. We've had case managers tell us, it's three to five years on the wait list, maybe as much as

20, maybe as much as 20.

When a client is denied services and pushed into crisis, the result is what? State guardianship in a group home costing more than four times -- more than four times what the 29 waiver would do. Because the state guardianship has a cost too and none of that says anything to the affects of the family. And instead of supporting these families for the key people that they are, these families are bullied and just more things are dropped on them and more paperwork and more responsibilities to the point that they crack. And they crack and then they take that choice letter and they check ICFMR.

MR. SAUCIER: Steve, would you be willing to tell us what support would feel like for you? Describe what support should be for families because I'm very interested in that topic.

MR. McKENNA: What support would be for families?

MR. SAUCIER: If you were being supported by us, describe some examples of what that would look like, things we could do for you that we're not doing now.

MR. McKENNA: Wow, where do I begin? Where do I begin? Let's talk about the grievance process. Are you familiar with the grievance process?

MR. SAUCIER: Uh-huh.

MR. McKENNA: The grievance process is intended to assure quality services are being provided. But yet when a client or guardian or family member wants to file grievance or complains about a service, they're told they have their choice of provider. They're deterred from filing a grievance. When they do file a grievance, the grievance process states that that provider has eight days to resolve the grievance. But instead what the grieved party receives is a response, and that response is just a boilerplate denial that this is happening with no attempt at resolution. Then when it goes to a level two with OADS, with the administrator of OADS, the grieved party receives another boilerplate letter from Mr. McKnight, in my case, that basically supports and defends these private providers that clearly aren't providing services in accordance with the rules and regulations. And then when you appeal for a hearing in this grievance process, nowhere in the grievance process documentation does it say that you can be denied a hearing. But at this level, the department employs their Army of AAGs which is I believe 15 AAGs defending DHHS with unlimited funds. And they request to the Office of Administrative Hearings that the hearing be denied. And that doesn't exist anywhere in the process. Clients, guardians, family members are not ever told any of this. The whole process plays out over a year while the client is unsatisfied, not receiving what they need, not supported and what is the end result? They may finally get to a hearing and who is the hearing officer? A department employee at Office of Administrative Hearings, and this is supposed to be an impartial hearing.

MR. SAUCIER: Are there other things? I'm hearing that you're very concerned about the processes that we use to hear complaints and grievances --

MR. McKENNA: Complaints and grievances, authorization of services. My sons both applied for 29 and 21 on the same day. It's the same application, right? Their 29 was approved within 30 days, about 30 days. The 21, no response for months. For months no response. It wasn't until I personally called up to everybody in the OADS phone list on the Maine.gov website. Finally after four or five months we got that they were approved and set at priority two. How many other people were in that stack of applications that aren't on a waiting list just because the department doesn't want to add to the waiting list?

MR. SAUCIER: And can I ask you, we have a lot of people who are receiving Section 29 who are on the 21 wait list and we don't have a lot of information about their circumstances, right? So if you don't mind my asking you, because although the list is long, about two-thirds of them are receiving 29 or other services so they're not, as some would say, receiving nothing at all. They're receiving services. So in your case, I mean are you willing to tell us what is it -- is it that you have an immediate need for 21 or that you're planning ahead because you know the wait list takes a long time?

MR. McKENNA: My son Gavin, 23 years old, is nonverbal, incontinent, has self-injurious behaviors and some aggressive behaviors. He is incontinent of both bowel and bladder. He has some serious needs. We've been trying to get shared living approved for him and everybody, including his current state caseworker says, there is no shared living home in the State of Maine that would take him.

MR. SAUCIER: So he's living with you?

MR. McKENNA: Yes.

MR. SAUCIER: And so 21, your hope would be that he could get a group home --

MR. McKENNA: My hope would be that he could get enhanced shared living with me, that's my hope. But the reality is that the department is not even allowing me to be his shared living provider. My wife is my other son's shared living provider, and the department is saying you can't have two shared living providers in the same address. So Gavin received a 29 funded opening on June 28th of '18 and still to this day receives no services. And the community case manager and the service planning party involved would not submit PCPs for him because the liaisons at OADS were telling them not to, were telling them that they cannot do this, that this cannot exist.

MR. SAUCIER: Yeah, I can't speak to your specific circumstances, but I can tell you what you're describing does not surprise me because there is a policy that essentially a second person in shared living is not -- there's no additional reimbursement. That's one of the things we're looking at --

MR. McKENNA: But you're misinterpreting it and the department is completely misinterpreting it. This is an agreement, this is a service. It's subject to the service provider tax. This has nothing to do with a location. These individuals pay a separate room and board, just as they do in a group home. The address has nothing to do with it. If my wife and I go to Wal-mart with 15 other shared living providers, the department doesn't divide the rate by 15 when we all walk in that door. But you're saying because my two sons live at the same address and the department has said and documented it in grievance responses, that my son can go live anywhere else, but he can't live in his home that he was born in with his father as his provider even though his father is a certified DSP with first aide CPR and SL med class training.

MR. SAUCIER: It's an issue that we're looking at, it's a rate issue --

MR. McKENNA: And we're talking about lack of services, and this is a golden opportunity for the department to expand this program to allow better services at less cost for these individuals. And I'm not saying that there's gonna be a whole lot of people like my son Gavin in these situations because there aren't gonna be a lot of DSP or shared living providers that are willing to do that.

MR. SAUCIER: Is it okay with you if we just move around the room now and then we can come back to you once we --

MR. McKENNA: Sure. I kind of wanted to rip down through these other things if you wouldn't mind.

MR. SAUCIER: Okay.

MR. McKENNA: So let's go to community inclusion. Natural supports are extremely limited for these individuals, and they're certainly not sufficient. The paid supports that have available to them are mostly three to one which, again, pushes individuals with higher needs into group home settings which results what? In less inclusion and more costs to the system. One to one supports should be supported and promoted. It would alleviate caregiver burnout, it would increase the quality of life, and it would decrease the ultimate costs on the department and on the system for their care. Person centered. This needs a better measuring method. Clients are forced to accept this best practices model rather than self-directed services. Case management should be targeted --

MR. SAUCIER: On person centered, before you leave that, I agree we need a better way of defining that. And as part of some work we're doing right now, we're particularly interested in that. So if you have thoughts that you can send us on what person centered means to you, that would be very helpful to us.

MR. McKENNA: I think it means person centered. To me, it's pretty black and white. Like I said, unfortunately, my personal history has been that it has not been that. That it has been what the case manager and the service planners from the provider agencies are willing to propose. And even when I show clearly within the regulations of the PC process manual that the plan must be amended for guardian/client approvals, they still are unwilling to amend it for that. So there's a serious disconnect there between the person-centered process and what clients are actually receiving and what clients are being pushed into signing when it's really not what they want or it's really not what they need.

MR. SAUCIER: So let's take one more from you, and then I'd like to go around the room, okay?

MR. McKENNA: Sure. Let's talk about choice and flexibility. The waiting list is preventing choices and medically necessary services. This best practices model is consuming resources that could reduce the wait list and could expand services. This choice of provider narrative is being used to force clients into accepting sub par services and prevent filing and resolving grievances, and that's not choice or flexibility.

MR. SAUCIER: Thank you, Steve.

MR. McKENNA: Go ahead.

MR. CARPENTER: Bob carpenter. I've been very shocked about what was going on during the LePage administration. One of the things that really shocked me was your organization where it widdled down to like five members. Could you call a quorum for any of the work that you could do?

MR. KEMMERLE: We rewrote our bylaws, yes, so that we -- the few voting members --

MR. CARPENTER: I would like to make a suggestion. If the governor doesn't want to fill seats, fill members, why can't the legislature fill them? Give the governor 90 days. If he can't fill it within 90 days, then the legislature should be able to pick someone out.

MR. SAUCIER: You have some new positions that have been appointed, right?

MR. KEMMERLE: No, it's -- there's such a backlog. There were hundreds of boards and thousands of appointments which were let --

MR. CARPENTER: I understand that.

MR. KEMMERLE: I'm in regular contact with the Department of Boards and Commissions which I'm not sure is more than two people, and they were focused on the appointments that had to be vetted by the legislature. And so we're a personal board and it don't require that we're --

MR. CARPENTER: Well, I'm just saying, I think if the governor doesn't want to fill them, then the legislature should fill it for him. I think it's that simple.

Second, I would like to -- to say what he was saying, to plead poverty so you can have a waiting list I feel is unconstitutional and discriminatory, okay? I also feel for 162 people, if you multiply 162 times 58,000 some odd dollars, it comes out to be like $15 million more just to fill up those spaces. There is no excuse that the State of Maine cannot fill Section 29. There is no excuse whatsoever.

The other thing I want to talk about is my daughter has behavior issues like he does, but not as big as he does, okay? My daughter is -- must be supervised 24/7 for her protection and the protection of others. The first year that she got transportation, she unfortunately untied the seatbelt to a wheelchair guy and basically the transportation provider kicked her off by the following Monday of that incident. As I remember, that Medicare requires a grievance process and that she should get the service during the 30-day wait. No, that didn't -- she was kicked off by the following Monday. During the first round -- the first administrative hearing, during the LePage administration, there was this obnoxious person named Mary Decker. The hearing was extremely adverse. I had no idea -- I've been dealing with disability issues all my life, and particularly with my daughter's behavior.

I used to go into a room and talk it over with the people, and we could work out a solution to some of the behaviors. We used a collaborative team process. With this thing, I was not prepared to play Perry Mason in that particular hearing. I lost it. I then called for another one which happened about a year later. I got Disability Rights into it -- oh, I also need to put out the other thing. The transportation provider, Mid-Coast Connector, their director is a bigot. He gave me a long list of slurs about mentally challenged people. And basically at the end of his long list, he said, I didn't want to provide any attendant to ride with her to supervise her. Well, the Disability Rights people came, they fought for an attendant that would supervise. We won. The problems are still going on. He tried to say, well, she's doing well, we want to take away the attendant. I said no way. She needs -- my daughter is not the only one in the State of Maine who needs an attendant to supervise her behaviors. I mean if she gets in a car accident and, you know, people are dazed or whatever and she walks off, I need an attendant to make sure that she stays there. I'm still fighting with this guy about an attendant. They tried to get rid of it earlier this month, and I complained about it. I told them, we're gonna have an administrative hearing, I know the law better, I know I'm gonna get Disability Rights. And I told them, you better get a lawyer because your bigotry in the previous thing, you know, did you in.

And the last thing I want to say is there is a real problem about the care in here. This is the third state I've been to. Texas, they -- they were like the way LePage was. But in education I mean it was wonderful. They really knew what they were doing, all right? Well, they didn't know -- they were really trying to find out what they needed to do at that time. And working with the McLean Independent School District was the most wonderful experience in my life. I do feel that they brought in all of the stars from autism. I got to meet them, many became my friend. I worked with the McLean Independent School District to implement these procedures. I think we got most out of her when they were in Texas. When we were in Arizona, they really hated education, they hated education like a passion. They -- I mean earlier this year -- they struck with everybody else. But Arizona had a wonderful system of adult services. There's no wait lists that I know of for Section 29. There could be for Section 21 or what their equivalent of what 29 and 21 are. I mean they were wonderful. Here is -- my daughter's behaviors, she got kicked out of two day programs because they could not control her behaviors. I mean she does not fight, she goes not hit, she is not aggressive like your son is, but she makes you watch her like a hawk. If you don't watch her for a microsecond, she's gone. And the other thing is is that there are very few trained providers. You tell them what -- I asked the person, do you know what social stories are? Doesn't know. Do you know what visual tools are? Doesn't know. Do you know what this is, the needs program? Don't know. So there's a real education problem with the -- with people who work with our people, a very acute problem.

And the other thing that sort of appalls me is last spring Spurwink and Pine Tree State had an autism conference. The state does not apply any money to. This November, which I'm going to, the Autism Institute of Maine -- and it's a very small autism conference, it's like a day, and there's like two break-out sessions or three break-out sessions and a keynote speaker. And, you know, when I lived in Texas, we had a three-day autism conference. We met the stars of autism, they all came there. I realize when I was there -- when I first started, it was during the administration of Ann Richards. And then when George Bush and the republicans took over, they really cut back the budget but it's still a hell of a lot better than what Maine is providing. I can't understand why the State of Maine is not supplying money, you know?

So that's all I want to say. I hope everyone else keeps it -- you know.

MR. SAUCIER: Thank you.

MR. KEMMERLE: Rich.

MR. ESTABROOK: Richard Estabrook, I'm on the board of Independence Association. I'm on the finance and executive committee. Each month we review the number of openings that we have. It's always 20, give or take, a couple one way or the other. All of those 20 staff positions have to be covered by overtime. And so it's just very difficult to operate under those circumstances, and I think it's directly related to the degree of reimbursement for the rates.

Secondly, I'm on the -- what's known as the three-person committee here in Lewiston, and I'm familiar with the three-person committee, the oversight of behavior modification plans, behavior management plans, et cetera, and I recognize that these -- this oversight process is burdensome. I happen to believe in it because I think oversight is necessary or else there would be abuses in behavior modification, but I think it's an unwise policy to have eliminated the behavioral add-on and I think that -- which was an additional payment for people who -- for the providers who are dealing with people who are going through this process and complying with the law and using somewhat aversive behavior modification and techniques. I think they need to be compensated for their extra administrative time in doing that.

Over the past four or five years, I want to echo what the gentleman from Shapleigh said about the grievance process. I filed a couple of grievances for people, representing people in the grievance process. Level one, usually the caseworker agreed with us as the claimant and would say so but just said it's beyond my pay raise, I can't do anything about it and it would go to the regional administrator. Well, the regional administrator wouldn't even answer the grievance. And I would have to write another letter and say your time is up, you haven't -- and I would amend the grievance to add that. And then the person wouldn't -- in one they did, in one they didn't answer the grievance. Then we just went ahead and filed -- I want to echo what the gentleman said too about the apparent lack of impartiality of the Department of Human Services hearing officers. Some are better than others, but the question is always there, to what degree are they just not being impartial? And I think it certainly creates the impression of not having a level playing field in the grievance process to have the hearing officers be employees of the Department of Human Services.

On the wait list, okay -- unless the -- unless the disparity in wages is addressed, then the wait lists are never gonna be addressed because the providers don't have the capacity to add more people to the system, especially after many years of the wait list being in place and in a system in which only the most needy persons get off the wait list. I am particularly concerned about the class two, the level two people on the wait list because even by the department standards and the regulations, they have been determined to have been -- they are determined to be at risk for abuse, exploitation or neglect, it's just not immediate, so it doesn't put them into the first priority one. But there must be four or 500 people at least on that priority two wait list. And I'm particularly concerned that as long as -- we know that they are at risk for abuse, exploitation and neglect, et cetera, and we're not doing anything about it.

Finally, there haven't been any comments on the transition practices between child services and adult services. There is a law in 22A, a special education law, that is supposed to control that and I, having dealt with that transition at times, I would say that the law gives relatively poor guidance around the transition process. It does create some rights, but it doesn't translate well into either enforceability or clarity. And I, myself, would offer to point out the places where it could be improved legislatively.

And finally I want to thank you personally, Paul, okay, because I perceive that there has been a change -- I see change in the willingness of the department to listen to people and to actually possibly have results out of listening sessions like this. So that's really been apparent, and I appreciate it and I thank you. I'm done.

MR. SAUCIER: Thank you, Richard. I just want to clarify a couple of points about the waiting list. It's a big problem and I don't want to talk it down at all, but things that people need to know, there is always some attrition on 21, some people who either die or leave the state and we use that small amount of attrition to continue to serve any priority one who comes to us. So that's just -- that we're able to do that, and that's a good thing. The legislature included funding for 167 new slots in the current budget and we're starting to take people off the priority two list with 167, it's not enough, but at least we are able to make a dent in the level twos.

MR. McKENNA: Steve McKenna from Shapleigh again.

I'd like to make one comment on that. You know, during LePage's administration, the state was able to pay off $700-something million in hospital debts. I think it's a pretty small step for the Mills administration to pay this $500 million waiting list and get these people served.

MS. WESEL: My name is Lisa Wesel again from Bowdoinham. I would just ask if there is a way to shift your thinking about the funding issues of having to fund the wait list. I don't know if there's ever been any study done. It might be a useful thing to do to study the loss of productivity of parents who have taken on the full-time caregiving role. I had a -- I went to the long-term care meeting, and there was a woman who was talking about this dream job she gave up to take care of her son. I give up a union job which is a rare thing these days with retirement and health insurance and all of these things. I looked at the contract to see what I would have been paid now if I had stayed with that job. It's horrifying that I don't have that job. But, you know, when my daughter was diagnosed and she had all of these problems, sometimes it was not the caring for her that was so hard, it was the working in the system that took all of my time. All of my time at work was dealing with DHS and dealing with health insurance and that was so hard. Even with an understanding boss, that was so hard that I had to stop working because that has to be done between 8 and 5, and I couldn't work anymore. I figured we're gonna invest. I was very fortunate that we could sort of downsize enough and my husband earned enough that I could do that. We gave up the idea of ever retiring, it's not gonna happen. And I work as a freelance writer so there's some work I can do at home. But if anything happens to my husband, we have no health insurance, we have no nothing. And so there are so many families that at least one person can't work anymore because they're taking care of either a child or worse when they're adults. When they don't have school anymore and you fall off that cliff and you didn't get the transition, you don't have the services. And I think that would be an interesting study to do, to quantify somehow the loss of productivity of thousands of families in Maine who are no longer paying into the tax base. It's not just a cost to take care of these kids, it's an investment in the productivity of the people who live here. Because our family now, it's 20 years that I haven't had a good job. That's a lot of productivity to lose for a person, and it's not gonna get any better. I mean I'm 55, I'm not gonna get a great job now any way. But my daughter is on this wait list. She will always be on the wait list. We joke about, you know, opening a meth lab in our basement so she's less safe and then maybe she'll get off the wait list. But now she's in a safe family with two parents and she's not gonna get off that list so I will never be a productive employee again for the rest of my life and that's -- that's a loss to the state. That's a loss to the taxpayers, that's a loss to our spending ability. We have shrunken our lifestyle. Fortunately we were able to do this. There are a lot of people who can't have one person stop working. We were lucky that we could. But if that could be quantified, that might change the state's thinking about how much it costs to take care of these kids because there's a huge loss when you don't. Never mind the humane loss of having these people properly cared for. Having my daughter have an independent life away from her parents and having the peace of mind that when we die, she will be cared for.

MR. SAUCIER: You know, there's a possible model for what you're proposing. You may be aware of

AARP's national study of caregiving, unpaid caregivers for elderly people. And that study has had a lot of influence and impact because it's a huge number. It's bigger than the amount of money that the government is putting in so that's a good idea.

MS. WESEL: Right. And the difference is the -- and I've taken care of, because I'm home, I'm in charge of taking care of all of the old people in my family because I'm home. And this is gonna sound sort of crass, but that's a very intense job for a distinct amount of time. Taking care of an adult child with disabilities doesn't stop. There is no endgame. If all goes well, she will outlive us. So that's a -- that's forever. So the amount of care that goes into -- this was something that I was thinking of when I was at the long-term care commission meeting today. If you think of the amount of care that goes into taking care of people at the end of their life, it's 10, 15, 20 years and it can be very intense. Our kids start aging in place at 21. So you're looking at 50, 60 years of care. So there are fewer of us. I know Maine has a lot of -- is the oldest state in the country. There are many, many seniors that will need this kind of care. Our kids will need it longer. So if you look at it in just man hours or the amount of care, I think it's -- our kids

require more because of the length of time that they're gonna require it. And if it comes from parents, that's a huge loss of productivity. I don't know who would do that study, if it's the Muskie Institute. I think it would be an interesting study because I know of many, many people who had to stop working.

MR. SAUCIER: Thank you.

MS. HUMPHREY: Kim Humphrey, Auburn. A few other costs, the human cost of waiting. I had -- my son had his quarterly meeting this week and I felt really scared when I found out they're down two staff and he can't -- he has to have his full staff to get out in the community, and you take so long to build out these activities and you need a regular routine to keep them up because he will lose his ability to -- he'll get complacent if he doesn't do these things and he's got these 12 meals on wheels clients and other activities that he's grown into. And if I think if they're having trouble now and then you go up the minimum wage, he's on the line of someone who could easily be civil or uncivilized and going into the stripping and not using the toilet and aggression and where he could easily lose that placement if that happens and then -- and I'm speaking for other people like this too that have these behavioral challenges. So there's a cost of like

displacement into really horrible settings like if you get stuck in an E.R. or a hospital. If you could measure those costs, which aren't cheap, and the quality of life that the individual suffers, that -- I would add that into the study. As well as like I have -- I'm divorced, and we had several years of living in duress. And you can't say -- who knows exactly why a marriage falls apart, but the cost -- there's a financial cost to not supporting families too. Also, the days that people are on a waiting list are days they never get back. You only have one life. And so really it's a matter of valuing humanity and finding -- you know, finding ways to meet people's daily needs. I think that's the solution.

I'm decluttering my house and I found I had extremely well-documented laws, like 10 to 15 years ago and it was the same things. And so I just feel like the concepts -- I think we get a lot of great concepts. You want something across your lifespan, you want inclusion and choice but you don't have choice if you can't go out and you lose your skills, you don't have a choice. So the heart is going into some of these concepts, but I think we need to beef up the value and find a way to really make it work.

MR. SAUCIER: Thanks, Kim.

MR. WAGONER: Larry Wagoner, Independence Association. I'm a DSP and I'm a field supervisor. When an employee leaves, turnover, sometimes they're gonna go get a better job with more pay or an employee is out, my job is to fill that slot. I work in a program called community living where it's in-home support. So sometimes I'm in the less than enviable position. I have to take somebody out of serving this particular person and put them into one with a perceived higher need. That leaves the other person -- some of our people can leave independently, but nobody is doing that person's ADLs or maintaining their skills. Or if it's a person with a parent working, then the parent needs to either take a day off. Then you have your lost economic productivity. The worst part of is it what you're doing to the person without the service for the day. Now, this may not seem as bad as some of these things, but if I'm supposed to work with a gentleman and do a woodworking project or take him fishing or something like that, that person is crushed. Or if their trusted staff for many years has left because they can't afford to do the job, then that person's crushed. They need to get a new staff, we need to train them how to work with that particular person. And also staff turnover is a big problem at residences. I've worked at residences, that's not where I work, but sometimes to help out. And if a staff is absent or late or we don't have anybody, then I'm kind of stuck there sometimes and that can happen a lot. So that, all the funding issues is critical. If you want to keep people's -- we want to help our people progress. We want to help them become more independent. It's hard to become more independent and progress in your skills if there's not enough staff.

Thank you. Thank you for listening.

MS. DECORMIER: I'm Jean DeCormier. For many years I worked for the Department of Human Services out of the Portland region. I have a master's degree in medical social work. My caseload were children who came into foster care whose parental rights were eventually terminated, but they were children with severe medical impairments and also terminally ill. I successfully placed these children for adoption. I had three children terminally ill. They all passed away, but they had the most loving adoptive families. But when you're doing an adoption assistance, I would be writing in there assistance also for burial costs.

One of my children, he was in the hospital. He couldn't leave the hospital because he needed a ventilator, had to be ventilated -- he had a condition called Moebius syndrome. It's very rare but what it is

is that the blood needs to have oxygen reinforced within it. He couldn't get out of the hospital. I couldn't get Medicare to pay for a generator in the home because the doctors said he can't be placed in a place that doesn't have a good generator because he needs a ventilator, and if the generator is not working, the ventilator is not working and he'd be back here and we'd be back and forth. What did I do? I went to my church, I spoke with the Knights of Columbus with the nurse, we gave them all the detail, they wrote a check for $7,000 and they gave me an electrician. He put a generator in this home. So I went outside the department. I used resources of people that I could find.

I was adopting a little girl myself as a single woman. I adopted her, brought her home. School, I was having trouble like the rest of you with school, with programs. I kept saying, she needs to be in a special program, I want her in this school. I want her removed from here, I want her in another school. One day she had an aide that was supposed to be walking with her from class to class. The aide left her. A girl got upset with her, picked her up and threw her off the second floor balcony. And thank God for a boy on the basketball team who caught her. Twenty minutes later, I get a phone call from the school that says, where do you

want her? Because they realized I could have brought a suit against them for the fact that the aide had left her. So we put her in a special school, a day treatment day school, she came home at night.

When it came to more behavior issues, I was grateful that I was, in some ways, an only child, had been left some income from my parents. I paid $52,000 a year for four years towards her education and boarding because I otherwise couldn't get it. I am grateful. She's 31 years old, she's being rather successful. She lives in a program, but she's being very successful. When I left the department also, I am now a shared living provider. I have a gentleman in my home. He's been with me 13 years. He's doing very well but he doesn't have a lot of the severe, severe needs. He has a day program he goes to three days a week, he has a job he's had now for 10 years part-time, quite successful in his job. My husband and I -- I'm now married. My husband and I are now concerned. He has a will, he has a living directive for the hospital. We set up a mortuary fund for him, it's half paid for. He pays a little bit each month on his mortuary fund. What we're concerned about too is like what happens what we -- when something happens to us, what's going to happen to him? We're concerned deeply for him. He's considered part of

our family. When get invitations, is so and so coming with you?

But my greatest concern -- the reason I came tonight is transportation. We've had a horrendous time with transportation for him. One night he's at work, snowstorm, 8:15 they call up and say, his ride is canceled for tonight and that's an 8:30 pickup, 8:30 p.m. My husband and I are on the highway coming home from a family activity out of state. I call him and I say to him on the phone -- we made sure he has a phone, we made sure he has money in his pocket. And I called him and I said, go across the street to Cumberland Farms and wait for us. It's gonna take some time, but we're on the highway, we'll get to you. This is our emergency system now. He has a telephone, he calls us. If transportation doesn't pick him up within the time they're supposed to, he calls us. No matter where we are, we will go and get him. So that's been my issue.

One night before we set this little plan up with him, he tried to get on the highway and walk home because he knew when he got on the highway, he knew what stop he should get off, where we would take the car and get off. And the State Police picked him up and asked him who he was and everything. And he gave him his I.D. and he gave him his little card. And we get a phone call and I said, yes, I'm sorry, this is what's happened, transportation didn't pick him up. I said, where can we meet you to pick him up? Well, that doesn't happen anymore, but transportation is a big problem. And that is creating a lot of the stress in our family, a lot of stress with him. I don't care if he gets stranded at home, but I care if he gets stranded at program, I care if he gets stranded at someplace else.

MR. SAUCIER: Thank you.

MS. DECORMIER: So I empathize with all of you, what you're going through. I mean we're very fortunate that -- and recently we've had, like all of you, we've had extreme change. We've had a job change, a job coach change, we've had a case manager change. We've also had a change in my supervisor at my agency. So there's all these new people. And we sat down and talked with him about this and he said to me, that's all right, I still have you. So the stability, though, and getting to know new people. And as I say, they come and go in your lives, they come and go. And it's very hard on our people, extremity hard. So --

MR. SAUCIER: Thank you.

MS. DECORMIER: I'm sorry. I have empathy for all of you. I'm sorry.

MR. SAUCIER: Are there others?

MR. CARPENTER: I would like to speak again.

MR. SAUCIER: Let's go to people who haven't spoken, and then we'll come back around.

MR. CARPENTER: Okay.

MS. MUJICA: Virginia Mujica from Infinite Potential. I would like to ditto what other people have said. The transportation issue is definitely a critical piece. It doesn't seem to be organized well at the head office because I know for a fact -- we are a small agency, and I know for a fact that they'll pick up someone and go right by someone else's house but then he'll call and say, they told me I don't have a ride and that's happened over and over and again. And that's just one small example as well as we've ended up having to transport clients home because, like I said, they get called and say we don't have a pickup for you. Luckily we're able to manage that for the small number of clients that we have. But in terms of, again, just the clients when they don't have that, they get frustrated, then they don't want to come to program, they lose that ability to maintain the skills or to gain skills. Most of our clients who have the ability to, again, possibly work independently and live independently and those skills are not being developed and then they want to

isolate more because they can't handle that type of inconsistency. Again, I understand transportation has been an issue, a long standing issue. But it did seem before this process, this company, this large logistic care was given this contract that the smaller company at least seemed to be a little more in tuned and can provide the same person and became familiar with the clients and that made a really big piece -- that the clients' anxiety would be decreased so that the anxiety of having, you know, a different driver, never knowing who is gonna pick them up, if they're gonna be picked up is very much an impact on the clients receiving the services they need and building those skills and maintaining them.

MR. SAUCIER: I will just say, transportation is an issue the commission has heard about just from about everybody that the department serves. And so she has an interoffice group looking at it, and they expect to have a public process just to hear more about it. But you're not alone in your concerns about transportation, I can assure you.

Others who haven't had a chance to speak yet?

MR. NDAYISABYE: Leopold Ndayisabye. Thank you for giving me this opportunity. I work for a group

home providers agency, and my concern is about the process to get the new location enrolled. That process is an overwhelming process. It takes like over 60 days to get a new location being enrolled. And that time you have to take care of everything, you're paying rent or just taking care of all that process --

MR. SAUCIER: To become enrolled as a provider you're saying, right?

MR. NDAYISABYE: Yes. Even after you are a provider because there's two different licenses. So you do have a license as a provider. And every building that you own, facility should have a license as well if it's over two placement, a two-people placement. And other thing -- that process is so long because you go to a third-party to get that enrolled. So you have to go around all of the offices asking -- just after submitting your application, and you can wait over 45 days. And you don't have anyone to like ask is that something missing, where the process is? They will just tell you it's in process, it's in process, just wait. And at the end they will tell you, oh, you were missing this after like 45 days. So you have to start over for some other paperwork needed. That's one thing.

Two, there is a policy called single placement related for some clients and these -- it's --

I do have a case which that's -- this young man has been going all other places, all agencies would not take him. So we take that gentleman, and he has been successful for many years, now he has been able to work. He is working at least 10, 15 days (sic) a week and he's -- I know it's been difficult for him just to -- first of all, to focus and due to his disability so it's a lot of things going on. However, that was, I would say, a success story. So what is happening? He's gonna be taken off just because where he's placed today, we have not been able to get a roommate. And in that situation, they call that as a single placement which the person is not approved for. So they don't -- the policy doesn't care about the outcomes, they just care about those traditional -- just without -- so when we've been talking about, you know, a person center approach and all these. So we need just to refute that, to make sure. Do we do for the client or do we do for policies and other things? So that's what I would say. Just like enrollment and those policies which really really make some people being vulnerable without caring about people we should be caring. And I empathize with everyone, parent, and I wish the first thing, to encourage and to help families who could be a part of service providers to take care of their beloved ones.

MR. SAUCIER: Thank you.

MS. DECORMIER: I'd like to add something about shared living. With shared living, I used to be able to do respite care for someone who was coming into a shared living program who didn't have a placement yet even though I have a person in my home. Now the restriction is that you can only have one person in the home under shared living, and you can't do respite any longer. So that makes it very difficult because there are people -- there are -- some of the young people that came and stayed with us sometimes a couple of days, sometimes a couple of weeks, one young lady a month and she didn't speak or talk or anything. She was just sweet, she used to just kind of like cuddle. She saw me at a shared living dance one night. She was gonna get into a limousine and she recognized me and it had been like a couple of years. She just gave me a hug and ran off and got into the limo. But we're not allowed to do that anymore. And it would be a blessing if you could have not a severely difficult situation. Some of the children I -- some of the young adults I hear here would require extensive care, and it should be a one-on-one in a shared living. But there are some who could come in as a shared living home could be developed for them. And a lot of people don't want to -- I hate to say it.

Having been an adoption caseworker and fostered children and adoptive families, there are a lot of people who don't want severe responsibilities. I'll say responsibilities. There are others who will take lighter ones. But there are people who are out there doing shared living with some, you know, really medically-involved people.

MR. SAUCIER: Anybody else who hasn't spoken, and then we can go to a second round?

MS. HAGAR: Dawn Hagar from Infinite Potential. I would just like to speak again about the work crisis. I know other people have said it, but I don't think we can say it enough. We can't pay people enough for the work that they need to do. We try to hire supports for people like this gentleman's children, and you're paying them 11, 12, $13 an hour. It's just not enough. The other part is the training. The people who are working with these people, we should be able to hire people who have educations, who have degrees, who know how to work with these people, not just people who have a high school education.

I also would like to say the same about case management. In our facility, we deal with case managers all the time and they're not trained well, like somebody else had spoken to. One case manager will be awesome

and know all of these programs and all of these things for these children, and then you try to get that service for another client and the case manager has no idea what to do. So training; huge, huge. Money, huge. Thank you.

MR. SAUCIER: Thank you.

Others who haven't had a chance yet? Anybody else before we open it up to --

MS. JOHNSON: My name is Gail Johnson, I'm from Auburn. I'm sorry that I came in late so I don't know if that's -- if my issue has been discussed by other people --

MR. SAUCIER: No, no, that's okay. It's helpful to hear when more than one person has the same issue. Believe me, many of you have similar issues so that tells us something right there.

MS. JOHNSON: I'm running into an issue that when I talk to other people, when I talk to staff people or other parents, a lot of people feel the same way and it's that we're advocating for our kids. And especially if we are guardians and still very involved with their lives. And it's really hard when Disability Rights is not allowing people to work with our kids the way they need to be worked with and supported. And to me, that's as much of a problem for keeping staff as it is -- as the money issue is.

MR. SAUCIER: Are you referring now to challenging behaviors and behavior plans and that kind of thing or --

MS. JOHNSON: Challenging behaviors and -- everything is their right, but they don't have any responsibilities or have to be decent to other people. And they can't have any restrictions, they can't have -- they can't have consequences, they can't take responsibility for things that they've done that they're fully in control of and it's just -- I find it very frustrating because I'm constantly being told if I had kept him home and still had him at the house, there's things that I can do but they can't do that in the group homes. But he shouldn't be doing what he's doing and getting away with it, and unfortunately he definitely is and he knows it. He knows what he's doing is wrong and he knows he's in control most of the time. And I've talked to a lot of professionals who are equally frustrated with not being able to sometimes really serve these individuals because someone's worried about their rights being violated. I just think that's gotten a little -- I'm not saying that there aren't people that need their rights protected, but there needs to be a little more common sense and I wish that -- a better balance. And then I wish that people would involve the guardians more. So anyway --

MR. SAUCIER: Thank you.

MS. JOHNSON: Thank you.

MR. SAUCIER: Anybody else who hasn't spoken yet?

MR. KEMMERLE: Would we all be sure to sign the sign-in sheet? I would love to have your e-mail addresses so I could maybe get some clarification on some of the issues that you raised if you would be willing.

MS. BENTLEY: I haven't spoken, Ann Bentley, John Murphy Homes. I think the thing that we lose sight of because of oh, the money; oh, the staffing crisis; oh, the everything is these are beating hearts that we're dealing with, these are people. And when I go home tonight, I know who I'm gonna see and I know that -- well, I hope all of you do too. That doesn't happen in the group homes. When I come home from program, who's the staff person gonna be and who is going to put me on the toilet? Who's gonna give me a bath? Have I ever seen that person before? Those are things that we need to think about with the staffing crisis. I -- you know, as I get older, I've been doing this work for 35 years. I've never seen this kind of a crisis that we're in where people are just being cared for. I'm not saying not cared for well, not being taken care of. I don't mean that at all. I just mean who is this person who is washing my face? Who is this person who is wiping my bottom? And that, to me, is the real crisis that we're facing here with our staffing shortage. We need to think about that because these are all people. We are all people in this together.

MR. SAUCIER: Thank you.

Are we ready for a round two?

MR. McKENNA: I am.

MR. SAUCIER: Someone just had her hand up behind you and then we'll go to you next.

MS. WESEL: Mine's quick. Lisa Wesel again. I just wanted to -- I didn't realize that you were not allowed to have more than one person in a supportive living arrangement.

MS. DECORMIER: You're not now. With my person, he was very helpful, he loved the fact that we were having someone come in to the home and be with us and he was -- he would do little things like help plan for little things but they won't let you have two permanently. But then to take away being able to do some respite to be helpful, you know, just seemed like, okay, the new regulation, you know? Did they worry about how much money I was making? Maybe that was it. The fee is $100 a day for respite. I mean that's quite a bit of money. And if you go a whole month, I think that's quite a bit of money. But the issue is giving quality care to that person while they're waiting and stressed about where are they going, if they can even understand that.

MS. WESEL: There's a two-pronged problem here. One is funding, obviously, but the other is staffing. So this staffing thing, everything that I've heard, that's a really hard problem to solve. There are not enough human beings in Maine, adults, to do this work right now. So even if you pay them more, there might not be enough. My thought was, if my daughter comes off the waiting list, is there even a place for her to go and there might not be. So I think it might make sense for the state to rethink -- to start working better with the resources it has. If it has some people who have lesser needs who just need somebody to make sure they take their medication who don't have -- who are not medically fragile. Like my daughter, her seizures right now are fairly well-controlled, thank goodness. If she doesn't take her medication and doesn't get her sleep, it's a problem. But she's not a very difficult person to care for. You can't leave her alone but she's not very difficult. She would do well in a home with another person. And, in fact, it might be better for her because it would be like the difference between being an only child and having a peer. She would love some company. She would have a friend. If it worked well, that would be a perfect situation. So if you have this, a network of families who are good and supportive and have room and have the capacity, why have a rule that doesn't let them do it? I mean you don't want to turn them into some big Dickensian house with a hundred kids in it, but two adults, you know, why does that rule exist even? It doesn't seem to make sense.

MR. SAUCIER: You got me.

MS. WESEL: But that's the kind of thing you could look at, just outside the box. Look at what you already have. You already have somebody like this who might be willing to have more than one person.

MS. DECORMIER: I just finished my renewal on my CRMA --

MR. SAUCIER: Let's continue around if we could --

MS. DECORMIER: -- my DSP. I mean, you know, you have all these things. Every couple of years you have to do these things. I just finished a round of doing all my renewals and stuff like that for one person who doesn't need all of that. I mean, yes, he has medications. Monday morning we fill -- and he's partly an assist. We fill his medication weekly tray. I say, okay, what's your safe medication, how are you keeping them safe? They are here. How do I keep our medications safe? It's in a "locked" over here. Okay, thank you. That's Monday morning, every Monday morning, fine. And, you know, he takes his own meds and I check every day that he's taking them, that's fine. He's very capable and very -- he's not even -- he doesn't even need much anymore really after 13 years.

MS. WESEL: I think sometimes we can be our own worst enemy with these regulations.

MR. SAUCIER: Steve has been waiting patiently here, and I want to get back to him.

MR. McKENNA: I guess I have. Steve McKenna again from Shapleigh. I just want to hit on a few things that different people talked about in the room, and I wrote down some quick notes on. Somebody had spoken about respite, and respite is a huge, huge issue for my family. And the problem with the regulations in the shared living model specifically, the department's position is that the respite is a component of the rate paid to the administrative oversight agency. But when you go into the shared living manual, it only says that the administrative oversight agency is responsible to assure that respite is available but it doesn't say that they have to pay for it. So from my perspective, the oversight agency is getting paid for the respite but they're not enforced to provide it, and there's no schedule for how much or how often.

MR. SAUCIER: How much do they provide to you?

MR. McKENNA: Zero. They just assure that we have natural supports that can provide respite, but there's no amount, there's no frequency, there's no duration, there's nothing. So, you know, if we can get one of our other adult children or a family member to provide some respite care, then we can provide some respite care. But it's just this very vague thing that is not enforceable and, you know, from my perspective, this is just a profit stream for the administrative oversight agency that's just not working out.

MS. DECORMIER: He is correct. If my person goes to respite, I have to pay it out of my stipend.

MR. McKENNA: Staff trainings. Look, I took the DSP training. That DSP training from the College of Direct Supports is completely insufficient to care for either of my sons, either of my sons. It so barely touches on intellectual disability or autism. It is more concerned about APS and about regulations and about things that do not train the person to actually provide the care that the DSP training is supposed to be for. So, look, I think the training needs to be more intensive, but I also think there needs to be some kind of a tiered payment system for the DSPs. I also think that there needs to be a tiered payment system for shared living, frankly. Because the State of Maine has adopted a system -- Connecticut has a five-tiered system, and the State of Maine does not. The State of Maine, if that individual only requires two hours of supervision a day verses 24 a day, like both of my sons, they get the same pay. So those people can provide shared living and they can both go to work full time during the day and leave that person home alone and they get the same rate as my wife for caring for my son 24 hours a day. That's not okay. That pushes people like myself, families like mine, into group home settings which then costs the state 250K a year instead of 58K a year. And I think that the administrative oversight agency also has to be looked at as well as how that payment is structured because currently the system is that OADS and MaineCare cuts a check and it's none of our business, you guys do whatever you can, do whatever you want, and yet these are all supposed to be independent contractors so that the department or the provider agencies don't have to pay them benefits and give them insurance and give them Social Security and retirement and workmen's comp, don't have to give them a minimum wage, don't have to pay them overtime. And when you do the math backwards from the rate that's paid, it's like $4.34 an hour that we're paid, $4.34. And what's the state minimum wage right now, 11 going to 12? And we're paid 4.34 an hour. When you take into consideration 16 hours a day of awake time and then figure in the overtime, it backs into $4.34 an hour.

MR. SAUCIER: Do you have any others because I want to --

MR. McKENNA: I wanted to talk about my boys have always been square pegs and their entire lives, everything that they've encountered has tried to pound them into round holes. And we talk about this being person centered, and it needs to be more flexible and it needs to be more person centered and it needs to be open to changes in the system. And instead of pounding every single person that has a diagnosis of I.D. and autism into the same round holes with the same expectations expecting the same outcomes, it's just a giant failure, that's all it is is a ginormous failure. You're gonna

get a small percentage of these people that will reach your outcomes and your expectations. A small percentage that can do work supports when you're trying to cram work supports down everybody's throat. A small percentage that have natural supports available and you're trying to push natural supports to try to save some bank. It needs to be more flexible. It needs to be tiered. There needs to be more --

MS. DECORMIER: Specialized.

MR. McKENNA: -- solutions to the problems that are at hand. Technology is a great thing that the department does not use. EIS is what, 20-some-odd years old. And, yeah, I know we're launching a new system but there's no mechanism for the clients or the family members or the caregivers or the DSPs. It's all this guarded system that nobody's privy to. We don't get billing records on a monthly or semiannual basis on what services are being billed against our son's services so there's no fraud protection from the government's perspective where the clients can say, wait a minute, what? This case manager wasn't out here this many hours, they didn't do this for me, this didn't happen, I didn't do this, I didn't attend this. So it's just ripe for fraud, and there's no way that anybody can do anything about it.

MR. SAUCIER: Thank you, Steve. I'm gonna move -- there are a few others who had a second comment --

MR. KEMMERLE: We're just going through the last five minutes. We can stay a little longer.

MR. CARPENTER: Robert Carpenter. Is the state trying to come up with a five-year plan, list out issues that you want to solve?

MR. SAUCIER: Very much so. We're looking for a -- we'll probably actually do 10 and then --

MR. CARPENTER: Well, why not list all of the issues?

MR. SAUCIER: Right.

MR. CARPENTER: I mean I realize there might be the 10 highest priority or whatever.

MR. SAUCIER: My view is that it's not gonna be possible for many reasons to fix all the problems all at once and I'm agreeing with you. I think being able to have a map that shows all of the things that we need to do as a system and then prioritize which ones we can do this year and which ones we can do next year and so on.

MR. CARPENTER: One of the things I would like to see in this state -- I sort of feel everything is disjointed. And, you know, the education committee,

the education department should be working with DHHS. I don't see that happening. And not having the education department put in money towards an autism conference on a yearly -- or a conference where adults, kids, and whatever, all of those issues addressed. And then also expand the autism institute. They stop at education. You know, when they grow up, they go into the adult system, you know? They need to start looking into that and what we can do for that as a resource.

MR. SAUCIER: Thank you.

MR. CARPENTER: The thing I see constantly is nobody knows what they're doing. When I lived in Texas, there were so many resources around. There was Kathy Palomo, there was Dr. Good. That guy was crazy but he was good. Do you know what I mean?

MR. SAUCIER: Thank you, thank you.

MR. GOODWIN: Very briefly, Todd Goodwin. I have been listening to some of the comments. I'd just like to get on the record too back to rates and, you know, logic of how services are funded and individualized needs and all of that. I know you know the issue, but for those folks that require and are authorized for 168 hours a week, care 24 hours a day, you know, we've got to do something about the rate being cut if they exceed 168 hours a week. I mean that just adds to this larger dilemma that so many people have spoken to. I just wanted to get that out there. Thank you.

MR. SAUCIER: Thank you.

Anybody else? Last word?

MR. KEMMERLE: Well, I'd like to thank everybody, and especially I think so many of your anecdotes really did get at what we were looking at. If we say we want a flexible system, you've showed us how a lack of flexibility affects you. And I think there were some good suggestions about how -- somebody said work with what we have and make some changes and increase -- and change the way we deliver services in a way that, you know, we want it to happen.

MR. SAUCIER: I agree, Mark.

And thank you all for coming. I do appreciate people taking part of their evening to come. I totally agree that the examples are especially rich for us because it's hearing about your experiences and how our policies play out essentially. So very, very helpful. And a lot of the things that people spoke -- I will say virtually nothing that you've talked about tonight surprises me because we hear these things from other folks so it's really a matter, on our part, of trying to figure out which ones of these are the most

urgent and how we can sort of lay out a way of doing -- improving the system over a period of time so thank you.

MR. GOODWIN: Thank you.

ATTENDEE: Thank you for listening.

MR. McKENNA: Thank you.

MS. WESEL: Thank you very much for doing these meetings.

MR. KEMMERLE: Thank you all for coming.

We're off the record.

(Whereupon, the above-named hearing was concluded at 6:59 p.m.)

CERTIFICATE

I, Debra J. Fusco, a Notary Public in and for the State of Maine, hereby certify that on the 26th day of September, 2019, personally appeared before me the within-named persons to speak in the aforementioned cause of action and that the foregoing is a true and accurate record as taken by me by means of computer-aided machine shorthand.

I further certify that I am a disinterested person in the event or outcome of the aforementioned cause of action.

IN WITNESS WHEREOF, I have hereunto set my hand this 26th day of September, 2019.

____

Debra J. Fusco
Court Reporter/Notary Public

My Commission expires: February 23, 2023