June 11, 2018

Minutes

Present: Ed & Suellen Doggett, David Cowing Kim Humphrey, Debbie Dionne, Lydia Dawson, Mark Kemmerle, Nell Brimmer, Patrick Moore, Jamie Whitehouse, Julie Brennan, Megan Salvin, Margaret Cardoza, Celeste Henriquez, Mary Chris Semrow, Peter Stuckey, Ann-Marie Mayberry, Erin Rowan, Julie Joyce, Darla Chafin, Cullen Ryan, and Vickey Rand. Via Zoom – (Bangor): Paula Matlins, Andrew Cassidy, Steve Johnson. (Sanford): Brenda Smith and Jerry Silbert. (Winthrop): Cathy Dionne, Ann Long. (Brunswick): Ray Nagel and Colleen Gilliam. (Farmington): Darryl Wood, Kristin McPherson, and Celeste Turner. (Waterville): Pam Cairnie and guest. (South Portland): Laurie Raymond and Lori Richardson. Facebook Live: 27 followers via Community Connect.

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

Cullen thanked Senscio Systems, noting that they have very generously covered the cost of lunch for our 2018 meetings! *For more information on Senscio Systems you can visit their* [*website*](http://www.sensciosystems.com/)*, or connect with them on* [*Facebook*](https://www.facebook.com/senscio) *and* [*Twitter*](https://twitter.com/senscio)*.*

**Cullen:** I wanted to start the meeting off by thanking Commissioner Ricker Hamilton for attending and speaking with us in May. It was great to have him here, and I hope that will mark a rejuvenation of attendance by DHHS – OADS and OCFS, and that it will open a dialogue between the Department and parents and other interested parties here at the Coalition!

I strive to make the Coalition an inclusive, information clearinghouse. People should have a place to find information easily, and have answers provided to questions. We have worked to do that here, and to bring you experts who speak to you directly providing you with information listened to here, and captured faithfully in the minutes.

I work to not interfere with presenters or their information.

Today I want to do something unusual, and that is to offer corrective information to some items you heard here related to the Coalition, from the Commissioner. He said a few things which might have seemed alarming to some, and at the risk of sounding defensive, I thought it wise to take a moment to provide corrective information, and again, just for those items that relate to me or the Coalition directly. They are as follows:

1. The Commissioner indicated that the relationship with the Coalition has become dysfunctional for various reasons. He said, “I hope I never see another press conference again. Constant finger-pointing and blaming does not build trust.” This implied, at least to me, that there was a pattern of Coalition press conferences with finger pointing and blaming of DHHS.
	* I wanted you to know that the Coalition has never held a press conference. I have personally been at some press conferences, but at any press conference where I was involved, I carefully identified myself as either a parent, or Chair of the MDSOAB. I am not empowered to represent the Coalition without an actual vote or endorsement from the Coalition on an issue of obvious unanimity. There has never been a vote to finger point or blame DHHS. In fact, I wouldn’t support it. I see DHHS as a key ally. I work hard to create a welcoming, respectful, inclusive, and collaborative tone in all aspects of what I do.
2. The Commissioner indicated that the Department was the only one advocating funding the waitlist – and that some agencies even spoke to it not being necessary. He indicated later that DHHS has “looked to fund it, and put money in the budget to fund it, and we’ve been a lone voice.” This implied, at least to me, that the Coalition has somehow secretly never advocated to end waiting lists. We do a good job taking minutes here, and I looked through them.
* When the Biennial Budget included funding for eliminating the waitlists in 2015, that topic was discussed at the 1/12/15 and 3/9/15 Coalition meetings (the February meeting was cancelled due to inclement weather). The Coalition continued to highlight the Biennial Budget process at the 4/13/15 and 5/15/15 meetings, and at the 6/8/15 meeting there was discussion regarding thanking legislators who advocated funding for the waitlist.
	+ The Coalition sent an action alert regarding the opportunity to testify on curing the waiting list at the 3/6/15 public hearing in front of the Appropriations Committee. I attended the 3/6/15 public hearing, and testified as a parent and on behalf of the Coalition (with endorsement), in support of curing the waiting lists, though I was careful to talk about not pitting the needs of one group against another. From the 3/9/15 Coalition minutes: “There are finite resources and significant support needs – we need to advocate for all.”
	+ LD 323, the bill to fund the waitlist submitted in 2017, had a public hearing on 4/3/2017, at which 21 people offered testimony, including the bill’s sponsor, Rep. Malaby, and then Deputy Commissioner Ricker Hamilton. Of the 21 items of testimony, 19 were in support of the bill (including Rep. Malaby, then Deputy Commissioner Hamilton, parents, advocates, and providers); 2 were neither for nor against the bill and instead offered information and context regarding the system of care. I was in DC during the public hearing on 4/3 but submitted written testimony on 4/7/17 in which I also identified myself as Chair of the Coalition (with endorsement). The testimony was in support of LD 323 (and LD 967 so the system could deliver services needed by funding of the waitlist). ([Click here for a link to the testimony](http://www.maineparentcoalition.org/uploads/2/6/1/1/26115022/letter_of_testimony_supporting_ld_323_and_ld_967_4.3.17.pdf))
	+ The Coalition sent five action alerts with information regarding LD 323, and offered sample testimony to support the bill. The action alerts were sent on: 3/16/2017, 4/6/2017, 6/5/2017, 6/14/2017, and 6/19/2017.

With those clarifications, let’s begin the meeting.

This is the second year the Maine Developmental Services Oversight and Advisory Board (OAB) has used the Coalition as a forum, where information will get out to a large, broad group of people through the minutes, which is exciting. Before we begin today’s presentation, I want to be sure to cover some important topics and updates in case we run out of time at the end of the meeting.

**DHHS – Office of Aging and Disability Services (OADS) and Office of Child and Family Services (OCFS):** No one was present from the Department. Waitlist numbers were provided to Cullen by Amy MacMillan in a different meeting.

**Waitlist numbers as of 5/30/2018:**

* **Section 21: 1703. Priority 1: 0. Priorities 2 and 3: Unknown. Since January 2018, 113 people have received Section 21 offers.**
* **Section 29: 0. However, they are behind on their processing.**

-It was stated that there were some action steps for this group and its members that came out of the last meeting with Commissioner Hamilton. Engaging in this manner is one way in which the group can continue to interact with the Department. These action steps included transportation, plain language documents, and the Person-Centered Planning (PCP) process, specifically the limitation of the PCP being in EIS.

**Lydia:** I am meeting with Margaret after this meeting to discuss ways in which we can follow up with the Commissioner’s requests.

**Cullen:** As to transportation, I’m still hoping to have LogistiCare present in the very near future. LogistiCare was scheduled to present today, however there are upcoming changes that they want to have publicly available before they present so they can speak to these changes, gather feedback, and answer questions. A representative from RTP has also been invited to present on paratransit, who was also unable to attend today. We will work to get them in the near future.

**Disability Rights Maine (DRM) -** [**drme.org**](https://drme.org/)

**Nell Brimmer:** DRM is Maine’s protection and advocacy organization. We’re a client-directed, civil rights organization, and focused on the rights of individuals with disabilities. I have some information to hand out, including information on Supported Decision Making, which was just recently signed into law as part of the probate code (learn more at [*www.supportmydecision.org*](http://www.supportmydecision.org)). We’ll be rolling out education and training, with which Margaret will likely play a large role.

**Federal Update:**

**Cullen:** The House attempted to pass an agriculture and nutrition bill (H.R. 2, Agriculture and Nutrition Act of 2018) but was unsuccessful. However, it appears that the House may attempt to revisit the bill in the very near future. This bill would cut SNAP benefits by more than $18.8 billion over the next ten years, and it would eliminate “categorical eligibility,” impose work requirements for people who are not “seriously disabled” or raising a child under age six, and impose other requirements/restrictions**.** This is something about which folks should be aware.

As I’ve mentioned at previous meetings, we are working under the FY 18 omnibus budget bill, which was very favorable to HUD programs, including increases to Section 8 in all forms, HOME, CDBG, and the Section 811 program, all of which provide housing to the populations about whom we care. Senator Collins played a key role in this, as she advocated for increased resources as Chair of the Senate T-HUD Committee. This FY 18 omnibus budget bill funds the federal government through 9/30/2018, and is historically the starting point for the House and Senate in drafting the next fiscal year’s (FY 19) bill. However, the President’s FY 19 budget would severely affect resources, proposing drastic cuts to programs that serve vulnerable populations, including housing and services resources. It appears that the House and Senate have ignored the President’s budget as it pertains to HUD programs, as both chambers have crafted their own FY 19 T-HUD budget bills. Both the House and Senate FY 19 T-HUD bills are favorable, include significant appropriations above the President’s budget request, and provide increases to HUD programs versus FY 18 enacted funding. However, the House bill would not provide enough funding to fund all Section 8 renewals, whereas the Senate bill would.

A few years ago, MaineHousing, in partnership with DHHS-OADS was successful in applying for HUD’s Section 811 program. Their application requested 67 Section 8 vouchers, targeted for people receiving Section 21 and Section 29. I’m not sure if this program is operational, as we have been unsuccessful in receiving updates about the program. MaineHousing has stated that they’re going to apply again, with the application being due next week.

-It was stated that OADS has commented that the program is very particular to certain settings, such as group homes, and does not allow for other, flexible, non-traditional settings.

**State Legislature Update:**

**Lydia Dawson – Maine Association for Community Service Providers (**[**MACSP**](http://meacsp.org/)**):** There have been some positive steps forward since we last met. The Appropriations and Financial Affairs (AFA) Committee met at the end of May and moved forward a small spending package, which included funding for DSP rates increases. The bills were folded into one spending bill (LD 924), which also included county jail funding and funding for elder direct care services. A Special Session has not been called, which would be necessary to see this funding actualized. However, in a recent gubernatorial forum, Ken Fredette, House Minority Leader, stated that they will “of course be coming back in a Special Session,” specifically highlighting DSP rates as well as, unexpectedly, funding for the waitlists. I’m hopeful. There’s certainly funding available in the budget. The AFA Committee is meeting again today, and it appears that they may be considering another spending package to include funding for children’s services, which has had strong bipartisan support. We don’t know anything for certain yet regarding whether they’ll convene for a Special Session, but these are certainly steps in the right direction.

I wanted to highlight some things currently happening in rulemaking. There is a proposal to create a children’s psychiatric residential treatment facility, which states it’s intended to bring kids back into Maine and out of emergency departments. We don’t currently know what the need is for restrictive settings. [Disability Rights Maine had an exceptional piece on this](https://drme.org/blog/2018-03-09). We don’t really know what the waitlists are because the State doesn’t collect data for people who are partially served. There are at least 300 kids on at least three separate waitlists; so, we know that there are at least 900 kids with no services at all. We don’t know what the need is for restrictive settings until we’ve tried every least restrictive option. This would be forcing kids into crisis, and creating a reliance where the only way you can get support is in the more restrictive model. I hope the Department will pull back on these proposals. The regulations have already been proposed and the comment period has ended. However, there’s still opportunity to be spokespeople for community-based services and least restrictive settings.

The Department adopted considerable changes to the rules that govern Adult Protective Services (APS) and reportable events, including large changes to mandated reporting. You should be aware that those have moved through and are in effect as of Memorial Day. The changes in a nutshell: We used to have one big set of regulations that covered every set of mandated reporting. The Department repealed that rule and proposed two separate rules – one that governs APS and one for other reportable events. With this, they carved APS away from everything else, as its own system, and the only interaction the community or someone reporting now has with the APS system is a phone call. You call APS, you hang up the phone, and that’s the extent of your contact. Previously, APS was in this integrated data system, where you would know if the case was assigned to someone, if an investigation was taking place, and you would know the outcome so providers could make appropriate adjustments to services. This process ended with the new regulations. There are also considerable changes in the reportable events regulations and a decrease of reporting requirements. For example, previously you would have to file a reportable event every time there was a medication error or refusal, for situations as broad as someone refusing to use a prescription for cortisone cream. Now, you only have to report an error that results in some type of injury. Also, after you report something you have to document remediation steps, which was always the case, but now you’re required to record it in the State’s status system and designate the case manager to check to ensure the remediation steps are followed. This is creating a system in which providers are checking providers, which doesn’t appear to be an appropriate or effective investigation strategy. The APS rules also establish a Mortuary Review Committee, which is an internal departmental committee that reviews aggregate data related to deaths of people receiving services, which will then attempt to determine if there are potential patterns. This Committee is not looking at any specific case, just aggregate deaths. The Department has stated, though not codified in rule, that APS reviews every single death.

-It was asked if the deaths of people waiting for service offers (on the waitlist) are included in this aggregate data.

**Lydia:** I would think that would have to be reported, because being on the waitlist means people are in the system, they have case managers. I have heard from a case manager who reported the death of someone on the waitlist, wanting to know next steps after making the report. The problem is, after it’s reported everything that happens next is unknown.

**Peter Stuckey:** As a provider, if you file a report, do you know if they open a case?

**Lydia:** No. Another thing that’s concerning to us is that if you call afterhours or on the weekend you may get a voicemail when you call – that would be your only interaction, leaving a voicemail.

-It was stated that it appears the OIG recommendations, and the follow-up report’s recommendations, were ignored.

**Lydia:** We all have our own different opinions. I think it has been the Department’s response that they are implementing the recommendations in the original OIG report, and that this is a result of that. I haven’t seen the Department identify any of the issues that we have raised. We continue to meet with the Department; we want all involved to be inclusive and transparent.

**Cullen:** It appears that this is an area in which the Coalition would benefit from more information.

**Lydia:** A few other Department initiative updates – the Maine Background Check Center is now functional and has corresponding proposed regulations. This moves DSP background checks into a centralized place. The problem is that it doesn’t have all of the required background checks for DSPs, such as Child Protective Services and DMV checks.

The Department is working on a new school-based policy. For people receiving services in conjunction with education programs or in school settings, the argument has always been whether the DOE (Department of Education) or DHHS should fund it. There will likely be upcoming regulations pertaining to moving this from DHHS to the school system.

Additionally, as of January 2019, DSPs providing in-home supports will have to complete some form of electronic verification when they enter and exit the home. There are positives and negatives associated with this, but this is one more requirement with which providers will have to comply.

**Peter Stuckey:**  Children’s services used to notify all parents of kids in a program whenever an allegation was made, whether there was any substance to it or not. This would cause unnecessary panic and crisis for parents. With all of this, the mandated reporters are mandated to report if they have reason to suspect, but they’re not investigators. The system only works if you accept that premise. You file a report, and you may not hear anything while the investigation is ongoing, and that, in fact, may be the right thing to do in order to avoid compromising the investigation. I need to hear more about what’s going on relating to this, because perhaps this plays into it.

**Lydia:** For example, a community member calls and reports a DSP abusing a client – with the way the system is currently structured the DSP’s supervisor has no way of knowing that an allegation has been made, and thus can’t take appropriate action.

**Peter:** It sounds like the problem lies in what happens when the phone gets hung up. Is APS’ response to the report immediate and serious? The investigative process determines whether that person’s supervisor needs to be notified or not. Another observation is that when you’re talking about what’s happening in the Legislature and Ken Fredette’s comment regarding including funding to end the waitlist – this hit a button that plays a tape in my head on repeat, as I can’t tell you how many times I’ve heard, “we can’t do anything about that until we fund the waitlists!” I hope his comments were sincere, but I don’t want to hear that tape play back again as an excuse for not funding other things.

**Featured Speaker: Mark Kemmerle, Executive Director, Maine Developmental Services Oversight and Advisory Board (MDSOAB).** [**mainedsoab.org**](http://mainedsoab.org/) **Topic: MDSOAB Annual Public Forum**

**Cullen:**  Each year the MDSOAB holds community forums across the state to pull people familiar with and/or receiving services together to provide input on how services could be improved, point out issues, and provide general feedback. 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, that Mark and the MDSOAB will continue, using this feedback, when it creates its annual report. We want to ensure that you all have Mark’s contact information (kemmerle.mdsoab@gmail.com) so that you can continue to provide feedback, even after the meeting.

**Mark Kemmerle:** The MDSOAB exists, per statute, to provide independent oversight over programs and services for adults with intellectual disabilities or autism that are provided, authorized, funded, or supported by the department or any other agency or department of State Government. The MDSOAB focuses on systemic concerns, versus individual concerns, regarding identification of needs and desires, timely meeting of identified needs, and effective service delivery. The goal of this forum is to gather information about the availability, accessibility, and quality of services. This acts as a feedback loop for the Department about how services are working. Last month, Commissioner Hamilton stated that he receives a lot of input from providers, but not as much from parents. This is an opportunity for parents to be heard. I spent some time looking at the minutes from last year’s forum, and comparing the feedback to the MDSOAB annual report. My contact information will be in the minutes *(Mark’s email address:* *kemmerle.mdsoab@gmail.com**)*. But truly, any time something jumps off the page for you let me know. I find with my son’s case, when something happens, an issue arises, it often comes out of the blue. It always seems to be something you didn’t expect. Please reach out to me and ask questions; don’t be bashful!

**Begin OAB Forum:**

Mark went through the topics individually with the group. The group provided feedback and had thorough discussions for each area of interest covered. The discussion for each topic covered is listed below. *[Due to time constraints and robust discussion, not all of the topics were covered; areas not addressed will be covered at next month’s meeting, as noted below.]*

**Topics for discussion** (-followed by comments from attendees)**:**

1. **Crisis Services:** - The system is slow to identify a crisis. Parents don’t have enough education/training regarding how to identify a crisis. Crises can happen incrementally. It’s hard for parents to know when their child, or their family, is in crisis because they’re so accustomed to dealing with the behaviors, attempting to deescalate, and comparing the current situation to previous ones where they have been able to prevail, and in comparison, the current situation doesn’t seem so bad. In-home support providers can be such great cheerleaders, that it can make it even more difficult to known you’re in crisis. A parent stated, from experience, that an out-of-state bed can look very appealing, and can better address a child’s needs, when compared to the insufficient crisis services in-state. It’s very difficult to determine the true number of crisis beds, let alone how many are actually available. The Consent Decree included 24 crisis beds, 12 of which were provided by the Department, and 12 of which were provided by independent providers. However, the independent provider stopped providing this service so the number of crisis beds was reduced. It is believed that there are four homes with two crisis beds each, for a total of eight potential beds. However, due to a number of different rationalizations, it is believed that the functional capacity is a total of four beds. The number of crisis beds is insufficient. The MDSOAB should look into the Department’s data collection regarding crisis bed placements and crisis requests. How does the Department know how many crisis beds would be sufficient, even in an ideal scenario?
2. **Other Professional Services:**
	1. **Transition Planning:** - Parents/families need to be involved in the transition from school to adulthood; they need transition training/planning too as it’s just as much a transition for parents. The laws, available services, and ways of individualizing care need to be explained to parents and more information needs to made available. Transition planning needs to start earlier than age 14; it needs to start as soon as possible. The lack of consistency with case managers is problematic, and it makes it difficult to plan for the future. There isn’t enough overlap between children’s services and adult services. Everyone needs to recognize that this is one more major leap, and there needs to be people available at the high school level who are really steeped in this information and can work with parents. The terminology is difficult – it’s hard for some people to wrap their heads around a “waiver.” [Voc. Rehab’s](http://www.maine.gov/rehab/dvr/vr.shtml) role isn’t clear for many parents. The Workforce Innovation and Opportunities Act ([WIOA](https://www.doleta.gov/wioa/)) has changed Voc. Rehab, and it has a lot of ground to make up. There is not a central information hub during the transition phase. Parents, families, and people supported are in the position of having to become experts about every facet of the system. Transition fairs are wonderful, but then you realize there are 45 different organizations, which is overwhelming. How do you begin to sort through all of that as a parent? Specialists in transition planning are extremely beneficial; the system needs more of them. The school setting gets parents accustomed to having someone take control, set meetings, develop next steps, and so on, whereas the adult system is not setup this way, and it’s a shock for parents. The people around this table are arguably the most knowledgeable in the state about the system – if people around this table are confused, imagine how difficult it must be for the average parent or family member to navigate. Even amazing teachers and children’s case managers don’t have all of the information needed – such as knowledge about waitlists, the potential to utilize and transition to Section 29 services while still in school to help bridge the gap and avoid the cliff of no services, and so on. Even when the people involved know about transition planning, when to start, what to do, and what services to look into, it still can all finally come to fruition too late and still be insufficient. The expansion of Section 29, and the ability to begin the service while still in school, is immensely helpful for transitioning from school to adult services, while avoiding the cliff of no services, and feelings of isolation and loneliness that can manifest when people are removed from the school setting to which they’ve been accustomed for the majority of their lives. This also helps to avoid loss of skills during transition. The Blueprint for Effective Transition, which this group created and was embraced by both OCFS and OADS at the time of its creation, ought to be fully implemented.
	2. **Respite:** -Parents need to be informed about respite options. *(This topic was not fully covered during the forum and will be addressed during part two at the 7/9 meeting.)*
	3. **Communication:** -A large portion of people having behavioral issues have trouble communicating them. We need more communication specialists.*(This topic was not fully covered during the forum and will be addressed during part two at the 7/9 meeting.)*
3. **Wait List Management:** -*This topic was not covered during the forum and will be addressed during part two at the 7/9 meeting.*
4. **Adult Protective Services:** - *This topic was not covered during the forum and will be addressed during part two at the 7/9 meeting.*
5. **Guardianship:** - *This topic was not covered during the forum and will be addressed during part two at the 7/9 meeting.*
6. **Case Management:** - *This topic was not covered during the forum and will be addressed during part two at the 7/9 meeting.*
7. **Person-Centered Planning:** -
	1. **Futures Planning:** -How much control do people have over their own lives? The person needs to be the center of every decision; everything should be self-directed. *(This topic was not fully covered during the forum and will be addressed during part two at the 7/9 meeting.)*
8. **Section 29 Services:** - *This topic was not covered during the forum and will be addressed during part two at the 7/9 meeting.*
9. **Work, and Finding Work:** - *This topic was not covered during the forum and will be addressed during part two at the 7/9 meeting.*
10. **Other Topics of Interest**
	1. **Transportation:** - *This topic was not covered during the forum and will be addressed during part two at the 7/9 meeting.*
	2. **Inclusion in the Community:** - *This topic was not covered during the forum and will be addressed during part two at the 7/9 meeting.*
	3. **Communication with Department:** - *This topic was not covered during the forum and will be addressed during part two at the 7/9 meeting.*

**Cullen:** We’ve only covered a couple of the topics identified and we’ve run out of time. I’m wondering if I can put everyone on the spot and see if there is interest in carrying this over to next month, and have this be a two-part forum? *(Everyone was in agreement, and Mark was willing and able to return in July).* I think this will be very beneficial, as there’s a lot to talk about! I want to thank you, Mark, for being here today and I look forward to continuing this dialogue next month!

*[Round of applause]*

**End of presentation.**

The next meeting will be on **July 9, 2018**

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

Unless changed, Coalition meetings are on the 2nd Monday of the month from 12-2pm.

***Burton Fisher Community Meeting Room, 1st Floor of One City Center in Portland (off of the food court).***