June 12, 2017

Minutes

Present: Julie Brennan, Margaret Cardoza, Jerry Silbert, Cathy Register, Liz Weaver, LeRene Wentworth, Jeffrey Jones, Nonny Soifer, Pamela Cairnie, Rory Robb, Rachel Dyer, Debbie Dionne, David Cowing, Lydia Paquette, Ed & Suellen Doggett, Jerry Silbert, Cullen Ryan, and Vickey Rand. Via Zoom – Bangor (UCPofME): Andrew Cassidy. Sanford (Waban): Morgan Jones. Auburn (John F. Murphy Homes): Ann Bentley, Kim Humphrey, and Darla Chafin. Orono (Center for Community Inclusion and Disability Studies): Bonnie Robinson. Presque Isle (Central Aroostook Association): Steve Richard. Gardiner (Uplift): Charlene Kinnelly. Misc. sites: Stacey Lamontagne, and Romy Spitz (with two interpreters).

Cullen Ryan introduced himself and welcomed the group. Participants introduced themselves. Minutes were not accepted; they will be considered at the next meeting.

*Thank you to Senscio Systems, who has very generously covered the cost of lunch for our 2017 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:** This is the first time 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 in case we run out of time at the end of the meeting.

We’re sitting on the precipice of some serious potential danger for services; and this danger is manifesting in a bizarre way. The U.S. House of Representative has already passed the American Health Care Act (AHCA), which would cut Medicaid by $839 billion over the next ten years, among other changes that would be detrimental to people with intellectual/ developmental disabilities (ID/DD). After passing in the House, this bill was sent to the Senate for consideration. At first, it appeared there would be debate in the Senate, with the normal array of hearings providing opportunity for discussion, debate, and proposed amendments to the legislation. However, there appears to be an effort to get Medicaid reform, which would replace the Affordable Care Act (ACA), through the Senate very quickly without a public hearing or amendments, aiming for the 50 republicans voting in favor, with the Vice President acting as tie-breaker. This is an unprecedented sequence of events. Though the content of the Senate bill hasn’t been made public, it appears like it could include the same type of reforms that would affect Medicaid or MaineCare, including block grants or per capita caps. This is very dangerous, because in Maine we don’t have the resources to pay for MaineCare; the state bills the federal government $2 for every $3 dollars spent. Maine doesn’t have any other funding mechanism to support populations such as people with intellectual/developmental disabilities. Maine is a state that leans heavily on the government to allow there to be adequate supports for people. If this bill were to pass, we would see a drastic reduction in the amount of funding in MaineCare, and it would be felt quite dramatically – including affecting funding for services provided by Sections 21 and 29. Senator Collins sits in a key position in regards to whether this legislation passes in the Senate; it would require a republican or two to stray from party lines to defeat this bill. This Coalition, as well as numerous individuals and Coalition members, sent letters asking both Senator Collins and Senator King to oppose the AHCA, which would cut Medicaid by 25% over the next ten years, be disastrous for people with ID/DD, and devastate Special Education, as well as vital services for people with disabilities in Maine. On May 17, a few days after meeting with concerned parents on the matter, Senator King took to the floor of the Senate to share the stories of two Maine people with disabilities who would be affected should the AHCA pass; he was remarkable. ([Click here to watch the video](http://www.maineparentcoalition.org/senator-king-senate-speech.html)). It would be very helpful for Senator Collins to act similarly, standing up for vulnerable populations. I would suggest that this group send heartfelt emails directly to her staff. Out recent action alerts have provided contact information for the Senator’s staffers as well as a template for crafting letters. ([Click here for the latest Action Alert](http://www.maineparentcoalition.org/action-alerts.html)). If you haven’t already taken the five minutes to tell your story and appeal to Senator Collins I would strongly encourage you to do so. I can’t think of something that would more dramatically affect support services advocated for by this Coalition than this. The Senate is expected to act on this bill before the July 4th recess, though it could progress much faster. Send something personal. Let Senator Collins know how important it is to have services for people with intellectual/developmental disabilities. These personal stories will help inform the Senator, so that she can make a good decision for people in Maine.

Additionally, Emily Kalafarski, Acting Associate Director of Developmental Services, emailed this morning stating that **s**taff from the Office of Aging and Disability Services (OADS) were unable to attend today’s meeting. She mentioned that there are drafted rule changes for Section 21, and that OADS staff would be happy to discuss this at next month’s meeting; I would welcome them to present next month on this topic. The hope is that OADS will work collaboratively with this group before they go into formal rule-making. Emily also provided the waitlist numbers:

**Waitlist Numbers as 6/12/17:** Section 21 – 1550: Priority 1 – 0; Priority 2 – 539; Priority 3 – 1011. Section 29 – 0.

**Cullen:** Additionally, we have been following LD 323, sponsored by Representative Malaby, which would provide funding to cure the Section 21 waiting list. This bill passed unanimously out of the Health and Human Services (HHS) Committee and the House, passed the Senate, and is currently on the Special Appropriations Table pending funding for enactment.

**Lydia Paquette – MACSP (Maine Association for Community Service Providers (**[www.meacsp.org](http://www.meacsp.org)**):** We are watching two interrelated bills closely – LD 967, which would increase the Direct Support Professional (DSP) rates, and LD 323, which Cullen described. Both bill sponsors, Representatives Herbig and Malaby respectively, have requested that the bills be considered together because if we clear the waiting list but don’t increase the DSP rates, providers would lack the capacity to provide services to people coming off the waiting lists.

**Cullen:** We are also watching the biennial budget, which needs to progress through both chambers and be enacted before the beginning of the fiscal year on July 1st to avoid a state government shutdown. The budget includes $8 million to double the Section 29 cap, which this Coalition strongly supports. Nothing has been finalized, and we just heard last week that CMS ([Centers for Medicare and Medicaid Services](https://www.cms.gov/)) is requesting $51 million in repayment in connection to the 2013 decertification of Riverview; the Governor has indicated this he would like this to be included in the biennial budget, adding a $51 million unexpected expense.

**Lydia:** It’s still timely to reach out to your legislators, educate them about your and your family’s needs, and tell your story. Right now, legislators tend to get very protective of their districts, so hearing from constituents is important. Once it gets to this point in the Legislature it’s very easy to get forgotten about, specifically with this population that has historically been forgotten about. Remind legislators about the history, that people with ID/DD are no longer protected by the Pineland Consent Decree. We must apply pressure.

**Cullen:** Reaching out right now and telling your story, even if it’s redundant, is key. These stories will resonate with legislators and help them visualize why this is a priority. We have the numbers to make a difference.

**Lydia:** Keeping the message as simple as possible is beneficial.

**Cullen:** I want to thank our speakers for being flexible and allowing us to cover important updates before their presentation, as the OAB forum will likely take most the meeting.

**Featured speakers: Nonny Soifer and Pam Cairnie, the Maine Developmental Services Oversight and Advisory Board (OAB)** [**mainedsoab.org**](http://mainedsoab.org/)**. Topic: Maine Developmental Services Oversight and Advisory Board (OAB) Forum**

**Cullen:** The OAB is what followed the Consumer Advisory Board, which was initiated as part of the Pineland Consent Decree. When the Consent Decree ended, the judge noted a need to put in place an oversight and advisory group to follow-up the work of the Consumer Advisory Board. In 2011, legislation passed that formed the OAB, which would take on this role. The OAB 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. Each year the OAB 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 Nonny Soifer, Executive Director of the OAB, and Pam Cairnie, Coordinator of the Volunteer Correspondent Program (VCP), which falls under the OAB. I want to welcome you both, and thank you for being here.

**Nonny Soifer:** Before I begin I wanted to allow Pam to introduce herself and provide some information on the VCP, since the OAB forum will take up much of the meeting.

**Pam Cairnie:** I am the Coordinator of the VCP ([**vcpmaine.org**](http://vcpmaine.org/)), which deals specifically with one-on-one individual issues. The program provides volunteer advocates and friends for individuals who don’t have anyone who can take on that role in their lives.

**Nonny:** As Cullen said, I am the Executive Director of the OAB. I am new to this whole world. I’ve worked with some people with more knowledge of services and the service system to come up with a list of topics for discussion, with the opportunity to discuss other topics or areas of concern. Think about this as an opportunity to educate me as well. The goal of the OAB forums is to gather information about the availability, accessibility, and quality of services for persons with intellectual disabilities or autism and their families. I’m hoping the feedback and discussions today will help me get more clarity so I can be a more effective advocate.

I have a list of topics, and an opportunity to discuss any areas I haven’t included. I’m going to aim for ten minute discussions on each identified topic. I want to ensure that everyone has my contact information so that people can communicate with me directly with additional information, feedback, or concerns after today’s meeting.

(Email: [soifer.mdsoab@gmail.com](mailto:soifer.mdsoab@gmail.com) phone: 207-837-8025).

**Begin OAB Forum:**

Nonny went through each topic individually with the group. The group provided feedback and had thorough discussions for each area of interest. The discussion for each topic is listed below.

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

1. **Professional Services** (including medical, dental, therapeutic services, etc.): -When it comes to chronic disease and/or co-morbid diagnoses, there is a distinct lack of functionally trained medical providers statewide. Often, medical providers are not looking for causes, they’re looking to alleviate symptoms – this is not an accurate way to treat the problem. Medical and behavioral issues follow each other, they overlap. Far too few medical providers have a good grasp on how medical and behavioral issues are interconnected. Unless we do a better job reasonably soon this becomes exponentially more expensive and goes beyond the budget capacity of any state. We will all be better for this, as behavioral issues will decline, and in addition there will be functional improvement. Across the board we have fewer professionals willing to work in the field, and fewer people willing to take Medicaid/ MaineCare funding.

-Psychological services, communication services, and dental services are all important, and there is currently a distinct lack of access to them. People travel extreme distances to access many services. At one time, people had to travel all the way to Bangor to have access to sedation dentistry. Now, thankfully, there is a dentist in Portland providing this service. Lack of access to pediatric cardiologists in conjunction with dental care is problematic. People have a hard time finding speech therapists for more than one or two appointments. Occupational therapy has been inconsistent as well, with appointments scheduled so infrequently it’s very difficult to make progress. Communication services are imperative; they need to be emphasized and supported.

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

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

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

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

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

1. **Adult Protective Services:** Many people have had negative experiences with Adult Protective Services (APS). *(Individuals will connect with Nonny directly to provide more information on their experiences).*

**-**People outside of the service system, people in the community, have had difficulties effectively utilizing APS. The APS system and process is neither clear nor user friendly. When people have successfully navigated the system, following up has been problematic. Due to confidentiality, APS will not provide information to a concerned community member regarding outcomes of reports made to its office. However, in these scenarios, people aren’t inquiring about the outcome, rather that the information was given to the proper person and/or received in general.

**-**The individuals involved are not bad people, for the most part they’re very caring, but the system is structured in such a manner that allows them to navigate situations about which they’re unfamiliar and uninformed.

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

**-**The Department is currently in the process of reforming the APS regulations, combining them with elder services adult protective regulations. When these regulations are formally proposed, it is thought that they will be stripped down to the bare minimum that’s required federally. There was a stakeholders group when the regulations were being drafted, but there wasn’t anything proposed to react to so it was difficult to comment. There are ways the rule-making process could be improved if there was collaboration from inception all the way through to promulgation. People want to be ongoing collaborators, but to do so they need to know details when the Department is putting out rules.

**-**The Bangor Daily News (BDN) had an article a few months ago that centered on the lack of APS investigations and follow up. ([Click here for the article](http://bangordailynews.com/2017/02/12/news/state/investigations-into-the-abuse-of-disabled-adults-in-maine-have-slowed-without-explanation/)).

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

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

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

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

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

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

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

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

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

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

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

1. **Access to Services – Wait Lists:** It is difficult to believe that there is no one waiting for Section 21, Priority 1. Is it possible that people who would previously have been categorized as Priority 1 are now being categorized as Priority 2? Also, it’s difficult to believe there is not a waitlist for Section 29. People have been in a “queue” for months; this constitutes a waitlist. The infrequency of needs assessment/evaluation is problematic. There are likely people who have been on the Priority 3 waitlist for a very long time who might reach the level of need required to be categorized as Priority 2.
2. **State Guardianship:** State guardianship is currently in flux. Previously, people under state guardianship always worked with state case management. It will be interesting to see what state guardianship looks like when they’re not performing both roles at once. The new system design, with state guardianship uncoupling from case management, could make it more difficult to address problems systematically.
3. **Inclusion in the Community:** All the things that have been discussed today relate to and affect community inclusion. In a lot of ways, it’s the most important topic to discuss, but it tends to be a lower priority due to the plethora of other challenges. If you don’t have the medical services, or behavioral services, or crisis services, or planning services, or case management services, or an effective team process to tie everything together, it’s hard to tease out exactly where things start to break down. Everything is very interconnected.
4. **Any Other Topics of Interest: Transportation:** We get used to not having things and you slowly stop talking about them because it becomes status quo – this is the case for transportation. There is a distinct lack of access to transportation and it’s dehumanizing. There was a bill, crafted by SUFU ([Speaking Up For Us](http://sufumaine.org/)) regarding transportation, but they withdrew the bill. The Department acknowledged difficulties with transportation, but thought the proposed solution wasn’t the right fix; the Department wants to sit down with SUFU and discuss this. The Legislature requested that the parties involved report back on this.

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

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

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

**Nonny:** Thank you all for providing feedback. I’m going to take the information you’ve provided and use it to write a report. We’re trying to come up with priorities as well. I’m an advocate and an attorney; I need to know what to advocate for to feel most effective, so this is very helpful. Thank you!

**Cullen:** If anyone wants to follow up with any of these topics, you can connect with Nonny through the end of July. This is a feedback loop to create a report that talks about the state of services in Maine as they’re evaluated by the OAB. I want to thank you both for presenting today and using the Coalition as a forum. Thank you, and well done!

**End of presentation.** *(Round of applause)*

**Cullen:** Check out our website [www.maineparentcoalition.org](http://www.maineparentcoalition.org). You can find the title of any of our past presentations; Click the link, and you will go right to the minutes. There is also a forum on the Section 21 & 29 page on the website. You can log in and post questions/topics for other parents to answer. Additionally, the website can always use more pictures. Check out the recently updated Service Timeline. Our goal is to be an easily accessible information clearinghouse.

The next meeting will be on **July 10,** **2017**.

**Featured Speakers: Jack Comart and Kate Brennan, Maine Equal Justice Partners. Topic: Update on the 128th Maine Legislature, advocacy efforts, and ways the Coalition can take action.** Also featured will be **Emily Kalafarski, Acting Associate Director of Developmental Services, DHHS-OADS. Topic: Review and discussion of draft proposed rule changes for Section 21.**

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).***