August 14, 2017

Minutes

Present: Betsy Mahoney, Joy Mills, Kim Humphrey, Debbie Dionne, LaRena Wentworth, Mary Chris Semrow, David Cowing, Ed and Suellen Doggett, Rachel Dyer, Glenda Wilson, Kate Simson, Arthur P. Clum, Lydia Paquette, Todd Goodwin, Julie Brennan, Alli Vercoe, Kim Fletcher, Anat Levey, Liz Weaver, Margaret Cardoza, John Regan, Tammy Pike, Laura Pratt, Laurie Raymond, Jerry Silbert, Katrina Ringrose, Representative Drew Gattine, Cullen Ryan, and Vickey Rand. Via Zoom – Bangor (UCPofME): Elizabeth Whitmore. Winthrop (Autism Society of Maine): Cathy Dionne, Darla Chafin, Ann Long, Karen Mason, Emily Kalafarski, and Dan Sylvester. Misc. sites: J. Richardson Collins, Kellie Pelletier, and Romy Spitz (with interpreters).

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

*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:**  I wanted to start the meeting by welcoming Kate Simson, from Senator Susan Collins’ Portland office. Thank you for being here today!

**Kim Humphrey:** Community Connect and Disability Activists and Allies of Maine (DAAM) worked on a sign-on letter thanking the Senator for opposing cuts to Medicaid and standing up for vulnerable populations in Maine. (*Kim delivered the letter to Kate.)*

**Cullen:** Again, thank you for being here Kate. Senator Collins was true to her heroic nature and stood up for Medicaid, on three separate occasions, saying that the proposed cuts to Medicaid were not going to work for people in Maine. She made it clear that she would not tolerate cuts to Medicaid, which would negatively affect the vulnerable populations it serves. The Coalition sent her a letter of thanks, and you have the sign-on letter from Community Connect and DAAM. These groups were very vocal regarding the detrimental affects the formerly proposed changes to Medicaid would have for people with intellectual/developmental disabilities (ID/DD) in Maine, and Senator Collins listened to us very carefully. This ought to be applauded and loudly.

**Kate Simson:** I’m happy to be here; thank you for inviting me! The State staff are not policy-specific at all. I like to say that we know a little about a lot, whereas the staff in DC know a lot about a little. From the advocacy side, there’s a lot of parents in the room today, and even more who are connected with the Coalition, and I wanted to touch on how important your advocacy is and that it really does make a difference. Over the last year, we have seen a sharp increase in the number of people coming into our office, many of whom were fearful about the state of services. This made a difference; it changed my job completely. I’m meeting with more and more constituents every day. The Senator hears everything, all your calls, emails, letters, and so on. Keep up the good work. I’m located at the One Canal Plaza office in Portland; stop by anytime. I’m proud of you all; you are doing amazing work. Thank you. *(Large round of applause)*.

**Cullen:** I was in DC a few weeks ago, and had the honor once again of meeting with Senator Collins. She is well aware of the advocacy of this group and others to ensure Medicaid remained intact; she spoke on the issue thoughtfully, with a wealth of understanding regarding how vitally important Medicaid is for Maine. She evolved in her thinking due to each of us speaking out and letting her know what the implications would be should Medicaid be reformed into a block grant or a per capita cap. I want to applaud the Coalition, for how hard everyone worked, rolled up their sleeves, and got word out about both the House’s American Health Care Act (AHCA) and the Senate’s Better Care Reconciliation Act (BCRA).

Before we get started, I also want to say to the group that there has a lot of media attention recently expressing a great deal of outrage over the Department and its handling of care for people in both acute and non-acute care settings. This has also been expressed by people in and outside of this room. Starting in September, this Coalition will begin an education campaign to ensure that everyone who is part of or affiliated with the is Coalition is well aware of the history of the system of care for people with ID/DD. Charlene has twice provided to this group a history of Pineland ([click here for more information](http://www.maineparentcoalition.org/how-the-system-works.html)), and next month we will have Skip MacGowan, who worked at Pineland, present on this history. This in-depth history, including how the Pineland Consent Decree came to be, will span the course of the next several months. The concerns felt toward the Department must be turned into us demanding and expecting an open dialogue, quality care, and permanence of a system of care that will work for people with ID/DD. We want to ensure this system works well, right, and justly. The Coalition, the Maine Developmental Services Oversight and Advisory Board (MDSOAB), the Maine Association for Community Service Providers (MACSP), Community Connect, and Disability Activists and Allies of Maine (DAAM) are going to work in tandem to pull all the historical information together into one place, so this important history can be archived, and hopefully get everyone energized to work together to effect positive change. I hope that everyone will attend over the next few months.

-It was asked who the target audience is for the educational campaign.

**Cullen:** This in-depth history is primarily for us, to ensure everyone has information in hand as to what happened in the past, to prevent it from happening in the future. When Pineland was operational, it was at a time when people thought that vulnerable populations were not safe, had to be protected from society at large, and have safe places to live. This devolved over time into situations that were not pretty, were vastly inappropriate, and not in keeping with the intended goal of keeping people safe. We want to ensure everyone here has a working knowledge of what happened over time, and what finally occurred where people said they had enough, and held the state accountable. This will allow us to raise our voices collectively and effectively.

-It was suggested that these meetings be recorded.

**Cullen:** We can look into that, yes. DHHS was not able to come to Portland today, which is unfortunate because many of the people in this room have questions for Department staff. We need DHHS at the table in order to have an open, interactive dialogue.

**Arthur P. Clum:** Part of the historical piece is that Maine had a maverick Governor and that made a big difference. We’re lacking that now, in the way that it’s needed to change the system.

**Cullen:** We do have a maverick Legislature, which hopefully can help our cause.

**Representative Drew Gattine:** I wanted to echo Kate’s sentiments about how powerful the advocacy of this group can be. Going back to last year, this group fought back against the SIS (Supports Intensity Scale), successfully petitioned the Legislature, and accomplished a lot. This group of people is incredibly powerful and has the ability to bring issues to the forefront and effect change. Painting the sense of history, in 1992 I was in the Attorney General’s office, and knew a fair amount about the Consent Decree. I read the OIG ([U.S. Department of Health and Human Services, Office of Inspector General](https://oig.hhs.gov/)) report on Friday and looked at what’s happening. I worry people have forgotten the history that brought us to the point we are today. I see so many examples that have me concerned we’re going backwards. Without knowledge of the history surrounding all of this, the context and importance of that report last week loses some of its meaning. This is incredibly important context everyone needs to hear, both out in the community and in Augusta.

-It was stated that the report reveals many things, and DHHS has some fault, but there are also other factors. The issues revealed in the report, including heartbreaking stories, also speak to the importance of competent wages for Direct Support Professionals (DSPs), holding provider agencies accountable, and other work that needs to be done outside of the scope of the Department.

**Cullen:** The goal of the next few months is to educate ourselves, so we can do better and help the Department do better.

*(*[*Click here for more information about the OIG report, and related media coverage.*](http://www.maineparentcoalition.org/oig-report-information-august-2017.html)*)*

**Featured speaker: Laurie Raymond, Parent and Research Coordinator, SPARK Northern New England. Topic: Information about the SPARK (Simons Foundation Powering Autism Research for Knowledge) Research study.**

**Cullen:** Laurie Raymond is part of a very interesting research project as part of SPARK Northern New England. Thank you for being here today!

**Laurie Raymond:** I’m a parent, as many of you know, but I have also been a clinician for 32 years. Most recently, I was recruited to help with the SPARK study.

[***Begin Presentation (click here for presentation)***](http://www.maineparentcoalition.org/august-2017-presentation.html)

**Discussion:**

**Laurie:** I highly suggest that you check out the [SPARK website](http://www.SPARKforautism.org) even if you don’t participate in the study. Their research is incredible.

-It was asked if the study is looking at Autism subtypes.

**Laurie:** I believe the hope is over time to better understand it. They have a lot of long-range hopes about this.

-It was stated that it’s a good thing to be well-informed, however, concern was expressed that the results of the genetic testing could be used to influence parents’ decisions during prenatal care.

**Laurie:** There’s not a person I adore more in the world than my son. We had a lot of failed drug trials; his road hasn’t been easy because there’s been a lot of experimentation, and not in a scientific way. All of the SPARK sites are overseen by the Western Institutional Review Board, which is separate from any entity and separate from the Simon’s Foundation.

-It was asked if SPARK accepts samples from previous genetic testing.

**Laurie:** SPARK can’t. There’s a place when you register where you can say if you’ve previously had genetic testing.

-It was asked if someone requests kits for three people in the household if they will receive three separate kits.

**Laurie:** Yes, there will be multiple kits inside one box.

-A parent who participated in the SPARK study stated she didn’t recall being asked about biological siblings.

**Laurie:** Currently due to the website’s capacity you can only invite siblings who are 17 years of age or younger. When there is capacity to do so, siblings 18 years of age and older will be invited to participate as well.

-It was asked if there is a way to get information to other family members who live outside of the state.

**Laurie:** Go to [www.SPARKforautism.org](http://www.SPARKforautism.org), there should be a scrolling list and you can see if there’s a site in their area.

**Cullen:** Thank you very much for this presentation; this was great!

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

**Review of the updates to the Service Timeline, completed by Jenessa Grant, NH-ME LEND program and the University of Maine Center for Community Inclusion and Disability Studies.**

**Cullen:** Over the past few years Alan Kurtz has been able to send the Coalition NH-ME LEND program placements who have completed projects to help us develop informational materials for the Coalition’s website. Our goal is to have the Coalition’s website be an information clearinghouse. The most recent LEND placement revised and expanded the Service Timeline, available on the Coalitions website. The idea is that if you’re overwhelmed and don’t know what to do, you can go through the timeline to know how the system works and have a sequential series of action steps. But we want to optimize this tool, so please help. Go through this and please send us your additions or edits.

***[Begin Presentation (click here for the Service Timeline)](http://www.maineparentcoalition.org/service-timeline.html)***

**Suggestions:** -It was suggested to add links to Voc Rehab rights violations/grievances.

-It was suggested to add eligibility determination to the high school years and transition years’ sections as well.

-There was lengthy discussion regarding eligibility determination, specifically having this completed before turning 18 years old, and the various testing that occurs. When students have ID/DD the school district may discourage additional cognitive testing, saying that the IQ score is unlikely to change. Then, parents may agree to skip cognitive testing at the triennial IEP meeting. A person must have a functional score (activities of daily living) under 70 and a cognitive score under 70 to qualify as a student with ID/DD. The best course of action is to insist on the cognitive test every time you come up for a triennial IEP meeting; the school may balk, but be persistent. Beginning at transition age, if not beforehand, insist on the testing and follow up because otherwise it’s not the school’s responsibility to plan for your child’s post-secondary education. If you have a valid score within that period it counts and you can get services. It is vitally important that this testing occurs before the age of 18. You want to have an eligibility packet as soon as your son or daughter reaches the age of 18 to hand over to the State, as eligibility for Special Education and Adult Services are very different; you can qualify for one and not the other. There is an advantage to doing this in a school setting, and the school is obligated to pay for it. School personnel know your child, there is a huge advantage to have that. On the flip side, kids are used to being and functioning in schools; you can test kids in a school environment with school-related tasks, and they can appear to be higher functioning, but in a different environment it wouldn’t be the case. In school-based environments the focus is mainstreaming and focusing on the strengths of the individual; educators tend to be positive. Adults services is a different universe, where you have to come to the table and say he or she can’t do that. This is a huge culture shock for parents. People can also be cheerleaders; people want to be supportive of a person’s abilities. However, if you look at it from an eligibility point-of-view, with some of this cheerleading, even with the best of intentions, it may beg the question why the person is in need of services at all. Additionally, being physically able to do something, such as being physically able to move one’s limbs in a fashion that would allow one to dress him or herself or physically be able to put medication in one’s mouth is vastly different than having the functional and cognitive capacity to do so. Outlining the Adult Services eligibility process, step by step, would be very helpful. It is a cumbersome process. Additionally, having access to Special Education files is important. The schools are required to keep full records. You can photocopy your child’s evaluations to have a full historical perspective to hand to the person determining eligibility. Upon graduation or aging out, the files go into boxes and after five years are destroyed. This information is lost unless the parents/families have the foresight to request photocopies.

-It was suggested to broaden the services under Childhood Funding and to link to other MaineCare sections.

**Cullen:** Thank you for this helpful feedback. We will make revisions based on your suggestions. Please, continue to send us feedback; it will take your eyes to get it right. Thank you to Jenessa Grant, our most recent LEND program placement, and also to Karen Sites, the LEND program placement who originated the Service Timeline.

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

**DHHS Updates:**

**Office of Again and Disability Services (OADS):**

**Cullen:** It appears that Karen Mason has joined us at the Autism Society of Maine site. Thank you for being here, Karen.

**Karen Mason:** I’m also joined by Emily Kalafarski, our Acting Associate Director of Developmental Services, and Dan Sylvester, Director of OADS.

**Emily Kalafarski:** I’m now in the Acting Associate Director of Disability Services role. Cullen had sent some questions in preparation for today’s meeting, so I can start by answering some of those. First, is regarding the potential to use the emergency rule making process to enact the changes to Section 29, which were approved in the Biennial Budget. Yes, there is language in the enacted budget that permits emergency rule making, and that is our plan. We don’t have a specific date for you, unfortunately, but we’re working through this as soon as possible, and as soon as we have a date we will share it broadly.

**Cullen:** Thank you for speaking to that specifically. I wanted to say that the Coalition sent a letter to OADS requesting it use emergency rule making, so this is great to hear. Can you describe the steps that we can take that will make that move as efficiently as possible?

**Emily:** I can’t speak to every step. We’re working with the [Office of MaineCare Services](http://www.maine.gov/dhhs/oms/) (OMS), and at this point in time there isn’t much that’s needed. We don’t anticipate it will be a long process; it shouldn’t take much to make this happen. Right now, there’s just some internal work that needs to be done, to put the structure together to make that work.

**Cullen:** Even though you don’t have a date right now, will you be able to get a date to us soon?

**Dan Sylvester:** When we have a date we will certainly share it with you.

**Cullen:**  Last month we heard that it might take as long as six months to go through the emergency rule making process and submit a waiver amendment application to CMS ([Centers for Medicare and Medicaid Services](https://www.cms.gov/)). As you can imagine this caused me and others to worry. Do you have a sense how long this entire process will take?

**Emily:**  We are working to enact these changes as soon as possible. My understanding is that it will take less time than six months, but we don’t have final word on that, and other players, such as OMS, are involved. However, every indication is that it will be less than six months.

**Dan:** When we meet with OMS we’ll know more.

**Emily:** There was also a question regarding the rate increase in the budget, with the vast majority of services receiving rate increases, proportional to the services. This is currently in progress. We expect to have that finalized in the near future. Again, I don’t have specific dates, but will let you know when we have more information.

**Karen:** I want to add that in terms of the rate increases, the Legislature only included funding in the budget for rate increases for one year. The Coalition could reach out to the Legislature when they’re back in session requesting that this be extended, as what was approved has a sunset date.

**Emily:** I wanted to mention that the proposed rule changes for Section 21 have been posted, the public hearing has been held, and public comments are due on Monday, August 21st. A concise summary has been provided by the Department, and the full text of the proposed rule has been posted. [Visit the proposed policy/rules section of the Office of MaineCare Service’s website for more information.](http://www.maine.gov/dhhs/oms/rules/proposed.shtml) During this process, we can’t speak to what’s in the rule, but I wanted to let you know it was out. You can submit comments [directly on the website](http://www.maine.gov/dhhs/oms/rules/rulemaking_comments.shtml?id=760713), by emailing Rachel Posner, dropping them off at OMS, or mailing them to the OMS office (Office of MaineCare Services, 11 State House Station, Augusta, Maine 04333-0011). If you have any questions about submitting comments, you can contact MaineCare directly. **(**[***Click here for more information on the proposed rule changes, including how to submit written comments.***](http://www.maineparentcoalition.org/section-21-proposed-rule-changes-august-2017.html)**)**

-It was stated that, as presented at last month’s meeting, the proposed rule changes for Section 21 include expanding the number of members eligible for Section 21, Priority 1.

**Waitlist Numbers as 7/31/17:** Section 21 – 1549: Priority 1 – 0; Priority 2 – 538; Priority 3 – 1011. Section 29 – 0.

-It was stated that going forward it would be helpful if the Department reported on the number of people going on and off Section 21, Priority 1 monthly. The Priority 1 waitlist is continually zero; people want to know what the movement is each month.

**Emily:** We are happy to do that.

**Karen:**  We used to provide that information, but we took that off purposefully. There was confusion and people thought that people were still on the waitlist. This is totally doable, we’ll just want to report on that completely separate from the waitlist to avoid confusion.

-It was asked if they can report on reserved capacity monthly.

**Karen:** Yes, we can separate that out and provide that information as well.

-It was stated that there was a request during the Section 21 forums to report on the financial numbers for Section 21 monthly; how much of the appropriated money had been spent in any given month. It was asked where this stands.

**Karen:**  Providers have different billing cycles, so not every provider bills with precise regularity. We’d be giving numbers based on what was billed monthly. This data may not be meaningful for people but we can provide it.

-It was stated that this information could illustrate trends over time and could be very useful.

**Dan:** If that’s what folks are looking for we can look into providing that.

**Emily:** MaineCare providers have up to a year to bill for services provided, so this could also affect that data.

-It was asked how many Section 21 offers are made monthly. The waiver plan says five to ten per year for the next five years.

**Emily:** This is a good question. This is hard to determine because the needs of folks vary greatly. The Section 21 waiver application to CMS states 3,100 people at any point in time, and we have gone as high as 3,190 (unduplicated number over the year). This figure is what’s in the waiver plan which covers each year from 2015-2020.

-A parent asked if her daughter was 17, and will need to be in adult services with someone looking over her in order to be safe, what assurance is there that she is going to be cared for as an adult with special needs. It was asked how the Department meets the needs of our adult children who desperately need housing, specifically through Section 21 services.

**Emily:** I think that this is broader than Section 21, but if you’re looking at Section 21 specifically, there are some who pass away, there are voluntary terminations, and some involuntary terminations where people aren’t using the service. We’re operating within our current limits. Historically, there has been about a 75-person turnover each year. We haven’t had an increase in overall capacity since the Legislature funded 200 additional offers a few years back. In terms of thinking about services available for folks, it’s broader than just Section 21, but I know people want to be able to gauge the likelihood of getting this service. There are people who meet the reserved capacity criteria. Unfortunately, many folks remain on the waiting list. Determining the length of time someone will be on the waitlist isn’t something that we can do. For things to change significantly it would depend on the Legislature and Governor to appropriate additional funding.

-There was discussion regarding whether the Department was fully utilizing the appropriated funds for Section 21. It was suggested to postpone this discussion until it can be more thoroughly and thoughtfully considered.

**Cullen:** I agree that a deeper, thoughtful discussion is warranted on all accounts. Thank you to Karen, Emily, and Dan – it’s great to have you here and be able to have a robust dialogue. It’s wonderful when you can be here to answer people’s questions, because people have a lot of them. Thank you all again.

**State Legislature Update: State Legislature is out of session.**

**Cullen**: There’s not much to report as the Legislature is out of session. I wanted to say a special thank you to Representative Drew Gattine for being here today and for all his work in the Legislature! *(Round of applause).*

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

**Katrina Ringrose:**  DRM’s *Assessing the Use of Law Enforcement by Youth Residential Service Providers* report is on our website ([click here for more information](http://drme.org/news/2017/law-enforcement-youth)). Also, in general as we’re talking about waitlists for services for adults, it’s important to talk about the waitlist for children’s services as well.

**Other Business:**

* Southern Maine Agency on Aging (SMAA) – There are workshops for caregivers starting in the fall ([click here for more information](http://www.smaaa.org/family-caregiver.html)).

**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 **September 11,** **2017**.

**Featured Speakers: Skip MacGowan. Topic: A review of the history of the system of care for people with intellectual/developmental disabilities, including Pineland, and how people are working to archive and preserve this history.**

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).***