April 10, 2017

Minutes

Present: Erin Rowan, Bo Bigelow, Betsy Mahoney, Rob Lawler, Luann Lawler, Ed & Suellen Doggett, Liz Weaver, Peter Stuckey, David Cowing, Debbie Dionne, Kim Humphrey, Margaret Cardoza, Luc Nya, Jerry Silbert, Gil Moreno, Paula Schrank, Julie Brennan, Glenda Wilson, Cathy Register, Lydia Paquette, Yvonne Watson, Karen Mason, Rachel Dyer, Cullen Ryan, and Vickey Rand. Via Zoom – Bangor (UCPofME): Andrew Cassidy. Sanford (Waban): Morgan Jones. Auburn (John F. Murphy Homes): Ann Bentley and Darla Chafin. Winthrop (Autism Society of Maine): Cathy Dionne. Brunswick (Independence Association): Ray Nagel, Jen Billings, and Colleen Gilliam. Orono (Center for Community Inclusion and Disability Studies): Bonnie Robinson. Gardiner (Uplift): Pam Carnie, Charlene Kinnelly. Misc. sites: Stacey Lamontagne and Romy Spitz.

Cullen Ryan introduced himself and welcomed the group. Participants introduced themselves. A motion was made and seconded to accept the minutes from last month’s meeting. Minutes 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)*.*

**Featured speakers: Bo Bigelow, author and parent, and Erin Rowan, parent and advocate. Topic: Disability activism –** [**Disability Activists and Allies of Maine**](https://www.facebook.com/groups/405360463169873/)**.**

**Cullen:** The Coalition, which began 11 years ago next month, started as a place of advocacy and communication. It has grown to also be an information clearinghouse and an inclusive group of diverse people working collectively to improve the system of care and housing. Today we have two speakers, Bo Bigelow and Erin Rowan, doing collective advocacy work on behalf of Disability Activists and Allies of Maine (DAAM).

[**Click here for the presentation.**](http://www.maineparentcoalition.org/april-2017-presentation.html)

**Bo Bigelow:** My daughter Tess is 7 and has a rare disease – upon diagnosis she was the 8th patient worldwide with her disease. Now, there are 22 cases that we know of. Her disease is so rare it doesn’t even have a name. Part of my activism was figuring out what her disease is and then doing something about it. We mapped her genome and discovered that the mutated gene is USP7. However, even with that discovery the doctors didn’t know enough about that gene to provide any more information. At the time, I wrote a blog post, got people to share it, and 24 hours later I was on the phone with someone who runs a lab at a university in Texas who knew of other patients with the same disease as my daughter. In fact, I just got back from Houston yesterday where we had the first “conference of the families.” I am also a disability rights attorney.

**Erin Rowan:** My daughter Carrigain has Down syndrome; it was a surprise diagnosis upon her birth. I got heavily involved with the [Maine Down Syndrome Network](http://www.dsmaine.org/) right away; my husband joined its Board of Directors. I worked as an adult Occupational Therapist before my daughter was born. When she was born, I switched to pediatrics, worked for many years, and had my own practice. I realized that advocating for an inclusive education for her would take more time, so when she was in first grade I closed my practice and began doing advocacy full-time.

**Bo:** I came to this thinking political activism is something other people do; I gradually came to the idea that this is something *I* do. If we don’t do it, who will? With everything going on there’s a lot to think about and do. Instead of moving forward from the standards we had, it’s now a question of preserving things we thought were secure. What’s on your list? What would you like to see us do next with advocacy?

**Discussion:**

-It was stated that it has been easy to collaborate with DAAM and amplify each other’s voices. It was stated that a lot of things are already being worked on; to avoid reinventing the wheel being a pass-through for information is wonderful.

**Erin:** That’s the idea. We want to help make connections and help people get involved who otherwise may not.

-It was stated that the public education system is bifurcated, with children’s and adult services being separate. This has traditionally been a very challenging aspect of parenting and educating people with disabilities. It was stated that dignity of risk is paramount and very often gets overlooked. Caution was expressed regarding the press. It was stated that the press can sometimes look at one, small aspect of a story while ignoring the rest. However, it was stated that during past advocacy campaigns the editorial boards at newspapers throughout the state were extremely helpful. Strong relationships were built with [Bill Nemitz](http://www.pressherald.com/opinion/bill-nemitz-opinion/), and more recently with [Joe Lawlor](http://www.pressherald.com/author/joe-lawlor/), both of whom work for the Portland Press Herald – among others.

-It was suggested that Erin and Bo contact NAMI Maine ([National Alliance on Mental Illness-Maine](http://www.namimaine.org/)) and the [Maine Parent Federation](http://mpf.org/).

**Peter Stuckey:** There is a ton of knowledge and commitment in this room. There’s a community of children, their parents, and educators that have a similar commitment. It struck me, when trying to understand it from the outside, the opportunity and the potential that comes out of opening pathways – that’s a service to families, a service to the service provider community, and an incredible service to the taxpayers of the state of Maine due to the efficiencies that would come out of collaboratively planning for services. Groups get together to focus on a challenge in front of them that they’re passionate about and invested in. I know in the legislature I was surprised when I would look up and see other people tangential to me who had a similar set of experiences, energy, expertise, and collaborative spirit – but we had never made eye contact; when we did we could take things to a whole new level. You are new energy and it’s an opportunity to look around and see more opportunities for collaboration.

**Erin:** If anyone has any other ideas please feel free to email us *(Bo’s email address:* *bo.bigelow@gmail.com* *Erin’s email address:* *rowan62704@gmail.com**).* Let us know of other groups and/or listservs that we should be connected to or sign up for. Also, we would like to have a self-advocate working with us – send those names along as well, with information on how we can connect with them.

**Cullen:** I want to thank Bo and Erin for their informative presentation, well done! The Coalition is an open, two-way forum – feel free to use us as a vehicle for spreading information and we will do the same for you. The more that we get everyone who’s trying effect positive change for people with disabilities all working in unison the better we’ll all be. I appreciate the work you’re doing, your energy, and your enthusiasm, and I’m very happy to welcome you to the table.

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

**DHHS Updates:**

**OADS, DHHS -** [**www.maine.gov/dhhs/oads**](http://www.maine.gov/dhhs/oads)**:**

**Cullen:** First, I’m happy to announce that next month’s meeting will feature Jennifer Fales providing the presentation that has been presented at the Section 21 forums across the state. This was suggested at recent Coalition meetings and we’re pleased that OADS will offer this next month.

**Karen Mason, Associate Director:** First I want to introduce everyone to Yvonne Watson, our new Associate Director for Disability Services. Yvonne is in her second week with us; she started last Monday.

**Yvonne Watson:** I am retired from the Air Force, and moved to Maine in 2009. I previously worked to the VA for nine years but wanted to do something different. I’m very happy to be here.

**Karen:** We are in the process of wrapping up the Section 21 public forums this week. As Cullen said, at the next Coalition meeting we’ll provide that same presentation for this group. The plan following all the public forums is to post the PowerPoint as well as some of the questions we received throughout the process with answers.

**Waitlist Numbers as of today: Section 21 – 1496: Priority 1 – 0; Priority 2 – 510; Priority 3 – 986. Section 29 – 0.**

**Cullen:** The Section 21 waiting list at the end of December was 1399; it has since gone up by just shy of 100 people.

**Karen:** Last Monday, we went in front of the Health and Human Services (HHS) Committee to testify at the public hearing regarding LD 323, the bill which proposes fully funding the waitlist. We will wait to see what the Legislature does, but look forward to potentially funding (or partially funding as has happened in the past) the waitlists. A Save the Date has gone out for our second Community First Conference, being held on May 24th. Topics this year include assistive technology and supported decision making. We will duplicate the morning sessions in the afternoon to ensure people can attend what interests them. More information will be available once registration for the conference opens. I hope you all attend!

The Employment First Coalition has wrapped up its three-year work and its report will be submitted to the Governor and the LCRED (Labor, Commerce, Research, and Economic Development) Committee. Hopefully the report will be made public soon. There are 27 overall recommendations, with sub-categories for each recommendation. We look forward to implementing some of those recommendations.

**Discussion:**

-It was asked how many people per month from the Priority 2 waitlist are receiving service offers.

**Karen:** Right now no one is coming off the Priority 2 waitlist. We offered services to 200 people last year, but we don’t have any additional funding. Currently we are only able to make offers to people who meet the Priority 1 threshold or who are in the reserved capacity (looking to leave an institutional setting).

-It was asked what the fiscal note is to fund the waitlist.

**Karen:** I don’t know off the top of my head. We know that the Section 21 average per member, per year is a little over $105,000.

-It was stated that it appears the fiscal note is $47 million. It was also stated that, because of Medicaid reimbursement from the Federal Government, the actual cost to Maine is one third of that. [See later in the minutes on the top of page 4, line 5, where a reference to an accurate fiscal note figure is provided.]

-There was a question regarding transitioning people under state case management and state guardianship.

**Karen:** What you may be thinking of is the Governor’s proposal to eliminate some state adult development case workers. The Department is looking at moving away from fulfilling case management roles. As people leave their roles as case managers, those individuals are moving to community case managers. For those under public guardianship, the state will remain the guardian with the case management transitioning to the community. In terms of public guardianship, the State is always the last resort. When that must happen, we try to look at the least amount of responsibility in terms of that guardianship role, for example only being a medical guardian versus maintaining full guardianship. This is where supported decision making comes into play. Sometimes, unfortunately, we don’t start with people understanding that they have a choice, then making the best choice for them so others don’t have to, and then potentially moving away from needing guardianship down the road.

-It was stated that the quality of services for the money follows the person model is wonderful, however eligibility to qualify for the service states that to qualify someone must have been hospitalized for three or more months, or in a nursing home for three or more months. It was stated that people with ID/DD are less likely to be able to access this service due to deinstitutionalization.

**Karen:** We do have individuals with ID/DD in nursing facilities and they’re able to access this. This specific, earmarked money is for people to move out of institutional settings.

-It was asked if the Department has any thoughts on the Able Act.

**Karen:** That would be a question for Lisa Sturtevant, our Employment guru (*Lisa Sturtevant, Employment Coordinator
Maine DHHS – OADS, e-mail:**lisa.d.sturtevant@maine.gov* *phone: 207-287-9210*). We can ask her to come to a future meeting to provide more information.

**Rachel Dyer:** There was a bill in the last legislative session to introduce the Able Act in Maine, which turned into a Resolve, directing the State Treasurer to research implementing the Able Act in Maine. She reported back to the current Legislature what she found. Per her research, she believes that with some of the federal changes that Maine could do a transaction-based Able account without additional legislation. She is currently working with banks to try to get them to introduce this as an offered product. She’s hopeful that by the end of the year a bank will step up and offer this in Maine.

-It was asked where the Department stands on LD 967 (*the bill to increase the rates*).

**Karen:** Ricker Hamilton, DHHS deputy Commissioner, testified at the public hearing for LD 967 last week. Unfortunately, due to federal regulations through CMS ([Centers for Medicare and Medicaid Services](https://www.cms.gov/)) we are required to do a rate study to change the rates. We don’t have one yet. As we’ve said at the public forums, we’re committed to doing a rate study. At this point that’s where we stand.

-It was asked how the waitlists can be eliminated if direct support providers aren’t properly compensated. It was stated that this appears to be a real conflict. It was also asked how long a rate study would take.

**Karen:** I very much agree. The issue lies in the manner in which LD 967 was written; we’re not able to just increase the rates. I can bring some information back next month regarding all of this. To conduct a good rate study there needs to be good provider involvement. When Burns and Associates conducted the rate study in conjunction with the SIS (Supports Intensity Scale), it took about a year. During this process, some agencies came to the table, while others did not. Burns also looked at national data. It’s a process, which makes for a better outcome, but it does take time.

**Ray Nagel:** Did the CMS rule apply when the rates were cut in 2013 or 2009? And if so, then we’re working under a rate study done in 2005, effective in 2007; we’re working under the 2007 rate study which had us pegged at $25.30/hour while we’re paying about $22/hour now.

**Karen:** I can’t explain that; I’m not the rate setter. What was the cut in 2013? And what was it based on?

-It was stated that there was a 5% cut to home-based services, effective 8/1/13 and approved by the Legislature.

**Karen**: I don’t have the history there to be able to weigh in. Ricker testified last week and his testimony should be posted and available online. *(*[*Click here to view Ricker Hamilton’s testimony*](http://www.mainelegislature.org/legis/bills/getTestimonyDoc.asp?id=59567)*)*

**Charlene Kinnelly**: [The Office of Fiscal and Program Review](http://legislature.maine.gov/ofpr) (OFPR) put a price tag of approximately $24 million to fully fund the waitlists. The rate cut previously mentioned was a Department initiative. The original proposal was a 10% rate cut, eliminating the medical add-on, and moving to a per capita cap. The Legislature decided not to move forward with all those initiatives, but did make a 5% cut to the rates. In additional to these cuts, the service provider tax has been increased since the 2007 rates were established. Could you give an update on where the Department stands on finalizing the waiver renewal applications?

**Karen:** It’s my understanding that the rules for both Section 21 and 29 have been approved by CMS, as well as the waiver renewal applications. I’ll get information from OMS ([the Office of MaineCare Services](http://www.maine.gov/dhhs/oms/index.shtml)) on this.

**Lydia Paquette (MACSP):** The work session for LD 967, originally scheduled for this Wednesday, 4/12, was postponed so we can better understand the Department’s response, the CMS regulations that require a rate study, and information around the time frame needed for a rate study. We would love to give the Department whatever information needed that would expedite the process. Also, I’m wondering if you have timeframes around the changes to the Adult Protective Services (APS) rules and when the next set of Section 21 rules would come out? From going to the forums, it sounds like the Department is looking to make some changes to the Section 21 rules.

**Karen:** We’re in the process of looking at the Reportable Event rule, which is very outdated. We’re looking to use different language for reportable events, instead calling it critical incident reporting, and moving the abuse, neglect, or exploitation language under the APS rule. We have to work through what the process for rights violations would look like, so there is still work to do. The original timeline had us set to adopt these rules by September, but we may have to adjust that timeline. We will look to propose both rules simultaneously because they’re very much related. For the Section 21 rule it’s very early – I don’t have a timeframe.

**Cullen:** We would love to participate. There has been a change in leadership at OADS. Could you tell us more about that?

**Karen:** Yes! I should have started with this. Gary Wolcott retired and Dan Sylvester is the new Director of OADS. He couldn’t attend today’s meeting but we’re hoping that he can come next month.

**Cullen:** We would love to have him here, and both of you. As you can see, people had a lot of questions. Having OADS around the table is extremely helpful and we appreciate you being here. I also want to take a moment to thank the Department for including increasing the Section 29 cap in the Governor’s budget, and Gary for his leadership on this. This budgetary provision was voted Ought to Pass unanimously out of Committee.

**OCFS, DHHS –** [**www.maing.gov/dhhs/ocfs**](http://www.maing.gov/dhhs/ocfs)**:**

**Cathy Register:**  The Children’s Behavioral Health regulations are drafted, and slated to be posted either this week or next, after which a public hearing will be scheduled. Once the regulations are adopted we’ll be able to implement some of the rate changes, one of which being an increase to the specialized Section 28 waiver. We have added two new agencies providing Section 28 services – which specialize in the refugee and immigrant population but serve all populations. We’re getting more and more providers wanting to offers children’s services; it’s very exciting. Teresa Barrows, Behavioral Health Director, wanted to let this group know that the waitlist numbers are going down considerably. Children’s providers appear to be happy with the new system and we look forward to seeing the number of kids waiting for services decrease substantially. OCFS is also looking at a change of leadership. Jim Martin, Director of OCFS, is resigning at the end of the month, which is a huge loss.

**Cullen:** That is an enormous loss.

**Yvonne:** How much is the waitlist decreasing?

**Cathy:** It’s very different process form the Section 21 waitlist – but it’s going down significantly.

-It was asked how many children are being sent out of state for services.

**Cathy:** That’s a very good question. The residential piece is going to be coming underneath the Resource Coordinators’ responsibilities, which is exciting. I don’t want to provide incorrect information but there are some exciting changes coming up on that we’re working on. I will get back to this group with a number.

**Legislative Update**

**Lydia Paquette – MACSP (**[Maine Association for Community Service Providers](http://meacsp.org/)**):** I am the new Executive Director for MACSP. I’m very excited to be in this collaborative atmosphere. I don’t come from a lobbying background as Mary Lou Dyer did; I come from a legal background. I want to be as helpful as possible to the Coalition.

**Cullen:** Welcome, it’s great to have you here! I wanted to add that I have been hearing from some legislators that committees have been inundated with a high volume of people coming to testify, which is wonderful, but in some cases submitting written testimony may be a more effective and efficient option.

**Housing and other Updates:**

**Cullen:** I was in Washington, D.C. last week, and word on the ground is that the President’s budget isn’t palatable to anyone in Congress. President Trump’s “skinny” budget was released last month, and includes a $6.2 billion – or 13.2% – cut to HUD programs compared to FY16 to help offset a $54 billion increase to defense spending in Fiscal Year (FY) 2018. This would equate to a loss of 200,000 Section 8 vouchers already in use across the country, as well as the complete elimination of other HUD programs including the HOME and Community Development Block Grant (CDBG) programs. Though this is only the President’s budget blueprint, and Congress will take up the budget and appropriations, it is quite significant. Under this proposal Maine would lose 1100 Section 8 vouchers, which is very dramatic. We do not have an update on the HUD 811 program, as Dave Projansky hasn’t attended a meeting in quite some time.

**Karen:** I will ask Dave for a HUD 811 update for next month’s meeting.

**Announcements/Handouts:**

* Southern Maine Agency on Aging (SMAA) is hosting a training on 5/9: Intellectual Disabilities & Dementia: Basics for Family Caregivers. [Click here for more information](http://www.maineparentcoalition.org/postings.html).

**Cullen:** Before we conclude the meeting, I want to take a moment to thank Jim Martin and Gary Wolcott, on behalf of the Coalition, for their leadership. (*Round of applause*).

**Cullen:** As mentioned at last month’s meeting, we are contemplating changing the name of this Coalition. The Developmental Services Continuum of Care group is working on brainstorming alternative names. We will bring suggestions and recommendations back to this group.

**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. Take another look at the website from a parent perspective and make sure things are very clear, such as transition. Our goal is to be an easily accessible information clearinghouse.

The next meeting will be on **May 8,** **2017**.

**Featured speakers: Jennifer Fales, Initiatives & Clinical Review Program Manager, OADS-DHHS, and Karen Mason, Associate Director, OADS-DHHS. Topic: OADS Section 21 Forum Presentation.**

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).***