June 13, 2016

Minutes

Present: J. Richardson Collins, Debbie Dionne, David Cowing, Liz Weaver, Mary Chris Semrow, Ed & Suellen Doggett, Todd Goodwin, Ricker Hamilton, Jennifer Putnam, Sally Mileson, Julie Brennan, Margaret Cardoza, Patrick Moore, Luann and Rob Lawler, Megan Meehan, Cathy Register, David Lawrence, Romy Spitz, Adam Wilson, Grace Cooney, Amanda Eisenhart, Cullen Ryan, and Vickey Rand. Via Zoom – Bangor (UCPofME): Andrew Cassidy and Jon McGovern. Sanford (Waban): Michael Guay and Jerry Silbert. Auburn (John F. Murphy Homes): Darla Chafin, Kim Humphrey, and Ann Bentley. Gardiner (UpLift): Charlene Kinnelly. Winthrop (Autism Society of Maine): Cathy Dionne.

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 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 Ryan:** First, I want to welcome Ricker Hamilton, Deputy Commissioner of DHHS. Thank you for being here today. It is fantastic to have you at the table.

**Featured speaker: Todd Goodwin, CEO, Community Partners, Inc.** [**www.cpime.org**](http://www.cpime.org/)**. Topic: 2016 American Network of Community Options and Resources (ANCOR) Annual Conference overview: What is happening on a national level.**

**Cullen:** Last month it was suggested that the Coalition look at information from the national level. It was specifically suggested that we feature a presentation on the recent [ANCOR](http://www.ancor.org/) Annual Conference, which Todd Goodwin and Ray Nagel, among others from Maine, attended. Ray was originally scheduled to present today, but unfortunately has had a scheduling conflict and is unable to attend.

**Todd Goodwin:** The original intent was for both Ray and I to present, as we both attended the ANCOR conference. The conference was, as always, a wonderful experience and rich with information. The information we were hearing at this conference confirmed, among other things, that Maine is not unique in terms of the challenges and struggles facing the ID/DD service sector. Every system out there is facing challenges. I’m sure that Ricker could comment on that as well. It was heartening to see we are not unique in that regard, but at the same time it was disheartening that the service sector faces those challenges. At the conference there was interest and desire to share information, ideas, successes, thoughts, and so on regarding how the big “we” can help to effect positive change in the system. There are four areas we thought were worth commenting on, to continue the conversation as we move forward in Maine.

First, the big thing on everyone’s mind is the SIS (Supports Intensity Scale). We know what has occurred. We know that the Office of Aging and Disability Services (OADS) and the State have taken a good avenue for engaging people in what might come next. I had the good fortune of attending the OADS forum in Portland; it was a very valuable exercise. There was a genuine openness from the State’s standpoint to learn and receive feedback. At the conference we learned that there are many states dealing with SIS-related issues; the flavor was a little different, but across the board there wasn’t a state that we spoke with that didn’t have some concerns with the manner in which it was being implemented. Another take away is that, similar to what many of us in Maine have always thought, there isn’t a fundamental opposition to an assessment. It was helpful to talk with others to recognize it’s not an opposition to an assessment, but rather the assessment methodology. The thought is that we need to find opportunities to comment on what might be reasonable ideas or tools. At the OADS forum this was the chief question from the State – asking us our thoughts on this. Having OADS open to potential suggestions is a good sign. At the conference we agreed to keep communicating to put forth ideas regarding what might work. One state in particular, Idaho, did a nice job in talking about how they were able to marshal and organize a really broad coalition and work with their state in designing an assessment and resource allocation methodology that everyone understood and agreed with. There’s no reason this can’t happen here in Maine; with the family forums as the starting point there’s no reason we can’t go down that path.

The second item of note from the conference is transitioning to the Home and Community Based Services (HCBS) community settings rule. This is a finalized rule from CMS ([Centers for Medicare and Medicaid Services](https://www.cms.gov/)) that demands every setting that receives HCBS Medicaid funding come in compliance with a number of standards and characteristics that define community. There is the recognition that all of our service settings don’t necessarily meet those standards and characteristics. Maine is doing a nice job facilitating a way to come into compliance with that rule. At the conference, listening to other states, there were recognitions that came forward – we all share the true belief and are striving for all of our settings to be fully integrated, to really, truly be communities where true choice is apparent and without restrictions on often unrecognized freedoms that we all have. It’s going to be a lot of work. OADS has put forth a series of rich, meaningful planning meetings around this. We are working on sets of questions that are going to be the most meaningful and best way to gauge if our system is in compliance with the rule, and for where it’s not what is needed to get there. We learned that Tennessee’s transition plan has been approved. Since the conference two additional states, Kentucky and Ohio, have had their plans approved by CMS. With this, we have the opportunity to look to those plans to see if there are any thoughts that could be helpful to our own efforts. However, Maine is well on its way. We’re going to be field testing provider self-assessment surveys this summer.

-It was asked where more information on the rule could be found.

**Todd:** There are informational materials on the [OADS website](http://www.maine.gov/dhhs/oads/trainings-resources/initiatives/hcbs-regulations.html), as well as on the [CMS website](https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Home-and-Community-Based-Services.html). For many settings, the new HCBS rule will present some fundamental rethinking of service delivery and what our settings look like. There are a lot of standards we need to strive for. Also, I appreciate the transparency at the OADS forums that there will need to be some money appropriated from the system to make these changes.

-Someone from the group expressed possible concern about a provider self-assessment, stating that depending on responses it could appear that we are more in compliance than we are. It was asked if the self-assessment will be developed in a way to prevent this.

**Todd:** This is a great point and an excellent question. There are mechanisms in place to guard against this. Members of this advisory group have been spending a lot of time establishing questions, orienting/conceptual questions, that begin to set the parameters in which providers will respond. Also, there will be a follow-up validation check after the self-assessments are complete, through a random sampling methodology, which will include on-site visits. I should note that a large focus of this planning group is to, wherever possible, introduce validation coming from users of services as well.

**Todd:** A few other quick things – at the conference it was reinforced, and is good for us to recognize, that when broad coalitions, stakeholders, and other interested parties work with the State on proposals it’s critically important that we have an established and agreed upon set of data points. Thinking back to the SIS, we were all trying to illustrate points, however oftentimes the data measures were at cross purposes with each other and they weren’t connecting. One of the presenters at the conference was from [Burns and Associates](http://www.burnshealthpolicy.com/), and facilitated a good discussion around how important data is. Operating from a set of data, agreed upon by all parties, is imperative.

Lastly, and probably the highlight of the entire conference, was Tony Coelho, a former Congressman from California who was the primary sponsor of the Americans with Disabilities Act (ADA). Moreover, he was the author of the handful of amendments that followed initial passage of the ADA, and he led the charge early on for the Supreme Court to weigh in on the ADA. One of his key points at the conference, and we all know it to be true, is that there will always be a natural, instinctive, undeniable bias, stereotyping, and/or mischaracterization of persons with disabilities – it’s built into our culture. It’s not okay and it’s up to folks like us and the State to continue fighting and changing that entrenched cultural position. Tony Coelho used the passage of the ADA as a great example – when they were attempting to pass the ADA he would walk the halls of Congress and talk with people with genuine regard and desire to do things right; however, cultural biases got in the way and it was difficult to get it passed. It’s important for us all to keep this in mind and to not accept no for an answer; there is always a way to find common ground. If Tony had rolled over and accepted the prevailing thought around disability issues at the time, the ADA would never have passed. Hearing him speak to this was very inspiring. There’s a way to argue, push, and advocate in a manner that’s effective, proactive, and engaging.

-It was stated that DHHS should be thinking about processes across all of its offices. It was asked if this is how DHHS is thinking.

**Ricker Hamilton, DHHS Deputy Commissioner:** Absolutely. We are painfully aware that this plan is an unfunded mandate. We’ve figured that the validation survey will cost at least $500,000. However, it should be noted that Maine’s Olmstead Plan is far ahead. Nicole Rooney from OADS would be able to give an overview of the Olmstead Plan; the Department would be happy to provide that to this group. We are very much aware that waivers, both current and potential future waivers, have to come to the new standard. For well over a year we’ve been reviewing the rule, with all of the office directors coming together to participate; OADS has taken a lead role, but all of the other offices have been involved as well. The silence from the feds in the past regarding the transition plan for the HCBS rule has been deafening, so it’s very good to hear that other states have had their plans accepted.

**Todd:** In closing, good data and realistic, well-informed perspectives are key. At the end of the day groups have shared goals and a shared purpose, but we all face different demands. If we can recognize that and cut through the smoke to get to the real issues, we’ll all be better for it.

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

**DHHS Update:**

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

**Cullen:** Ricker, I am very pleased that you are here. This is the portion of the agenda where we hand it over to OADS.

**Ricker Hamilton, DHHS Deputy Commissioner:** Regarding the SIS, as the Department did the first time around we want to be very inclusive. No other state took the time, had the number of hearings, or worked as closely with families than Maine did throughout the SIS process. As Todd said going forward, and as is typical, we will be inclusive. Also, it’s important to remember that the proposal that came forward was a Maine proposal. Unlike other states, we didn’t make any assumptions. Some states went at this looking to cut costs; this was not on the radar for Maine. The misinformation, the disinformation that spread, scaring the people that we serve and their families – I don’t want this to be repeated. We can have differences, and we can speak to them, but let’s work together. It’s imperative that we have an independent assessment. I tried to work with a few executive directors and asked them if we could change the dialogue. Can we have a better system? Absolutely; I’m optimistic about the end result. However, I don’t want us to go through last year again. That’s why I want someone from the Department here at these meetings, and I will attend them when I can. If there’s something that feels like it’s not inclusive, let us know and we’ll look at it. In closing, the business model has to change; this is, for the most part, what I saw people hanging on to. In my role I personalize everything, using my son Sam as an example; when I make a decision as Deputy Commissioner I make it as if I’m making it for Sam. We want to have a system where the people we serve can be as independent as possible – if we don’t have that in mind for everyone than we’re doing a disservice. The HCBS final rule will be a hurdle for us, but the Department is absolutely committed to working with you because the models we have in Maine work. If it’s working, inclusive, and the best model we ought to be working towards that. The next time the Governor or Commissioner puts forward eliminating the waitlist I hope to have some of your voices in the room.

**Discussion:**

-It was asked what was meant by changing the business model.

**Ricker:** Maine deinstitutionalized long before others. We ought to celebrate that more often than we do. Currently, Maine spends about 70% on the group home model, whereas other states spend 20%. It’s time to take a look at that. There is nothing negative about that, some need that level of care, but it’s time to challenge the business model.

-Members of the group thanked Ricker for attending the meeting, for his point of view, and for focusing on putting the person first. Members also stated that having Ricker at the meeting shows a human behind DHHS.

-It was stated that the system design involves focusing on the medical model, which institutionalizes treatment for people. In regards to challenging the business model, it was asked what Ricker has in mind for the future.

**Ricker:** I don’t want to sound flip, but I want people with ID/DD to have the same options as everyone else. What other models do we have? The struggle is that we’ve asked providers to build a system with a reimbursement model for payment. We need to look at what bridging will have to be done during this business model change. Looking at what someone wants, how then do we create a bridge to move in that different direction. That’s a quality discussion that you and I can have. Someone might want to live with a little more risk than others believe is appropriate. We have to be able to have that conversation. We have to do something, because Maine stands out nationally for the amount spent on group homes, and we spend more per person too, but we need to do this in an inclusive way.

-The group thanked Ricker for his honesty. It was stated that in experiences with the Department, representatives don’t always convey the same message in the same manner. There appears to be a disconnect between how this plays out at the Department. Personal views and approaches sometimes get lost in the gears; conversations around the table stall, or a particular question is posed and someone dances around an answer. What trickles down from the top and what people experience is important. It was stated that letters from the Department, and the way in which they are written, can instill worry and fear. Additionally, often times people don’t understand the communication, and resources online are difficult to navigate, making it difficult to find answers to pressing questions.

**Ricker:** The next time you experience someone receiving a letter and having this response, will you send it to me? I will take a look at it. The Commissioner has heard this as well, so you’re saying things we’ve heard. (Email: [*Ricker.Hamilton@maine.gov*](mailto:Ricker.hamilton@maine.gov).)

-It was asked what process might be undertaken to identify where the bridges are needed for the changing business model.

**Ricker:** I don’t have an answer but I can envision it. I always go back to the individual. If you identify people who could live and wish to live independently, the next step is seeing what we can do to get the provider the pay to facilitate this. This is what I’m mean when I talk about a bridge. If an eighteen-bed facility has ten individuals leave for more independent settings, leaving only eight people, the facility faces closure. There needs to be some sort of financial bridge to facilitate people living independently while maintaining the provider’s ability to operate.

-It was stated that many times the Department is beholden to and driven by CMS mandates; a collective argument could be made to CMS.

**Ricker:** There is always that option, as well as working with our delegation. There has been some push back; we have been able to have some communication. Though, doing it together might be more effective.

-A family member stated that she had been approaching the SIS as a guardian, as a sister. She stated that she feels like she is always arguing on her sister’s behalf, who is in a four-person group home and truly needs to be. She stated that despite not having the SIS be a cost-cutting tool, the SIS would have reduced services in her sister’s group home collectively by a full staff person.

**Ricker:** That’s why we built in the extraordinary needs review process. With any new model there will always be a small subset who will be the exception. It’s looking at that business model. Is it necessary to have three-on-one support twenty-four hours a day? Maybe, but maybe not.

-It was stated that there is a difference between how we see these things and where the rubber meets the road. If the system can work for the exceptions, it can work for everyone.

-It was asked if the federal legislation allows for multiple models to be used, like the continuum model.

**Ricker:** There is room for different services, but with the HCBS rule it was one-size fits all and they didn’t really consider subpopulations whose needs might already be very well met. There’s room for many different types of services that meet our needs. The more we articulate that the better. The feedback we got from our transition plan was that they liked it a lot, but they haven’t put it in writing. I think that’s the type of talking we need to do. Oregon is looking at creating their own model and assessment. I’ve looked at that; it may be good for Oregon but I don’t see us taking that path for Maine.

-It was stated that Person Centered Planning (PCP), if done correctly, automatically implies flexibility. It was stated that the key is to figure out how the system that provides the funds has enough consistency so people know what to aim for while having enough flexibility to meet the desires, needs, and goals of the individual.

**Ricker:** It was always the intent that the SIS only inform the PCP, it was not going to replace it.

-It was stated that inserting the SIS into the PCP process, when it’s not quite working, also raised concerns.

-An educator stated that he spent a lot of time facilitating the move from the children’s world to the adult world – it truly is a cliff. It was stated that if one’s first exposure to the adult system is falling off the cliff it doesn’t help one’s disposition towards the system as a whole. It was stated that Jim Martin, Director of the Office of Child and Family Services (OCFS) is working diligently to make this transition easier. This group has discussed having an overlap in child and adult case management to facilitate that warm handoff. Parents establish strong relationships with the children’s case manager; an overlap would help soften the transition to the adult world.

**Ricker:** Maybe it would be beneficial to move from children’s case management to adult case management earlier.

**Cullen:** Ricker, I want to echo the thanks that have been expressed for you being here today. Your attendance has likely put people at ease, as they’re finally having direct communication with the Department, which is making decisions for their sons and daughters. This group has been starved since last July, when Karen last attended, as decision makers from OADS have not been at the table.

**Ricker:** That’s not going to continue.

**Cullen:** That’s fantastic. Like last time, we seem to be heading down the road in terms of coming up with a plan together. The last time, at a certain point it seemed that OADS became insular, finalized a plan, and then said that they couldn’t come to the table due to the rule making process. On our end this produced anxiety. It’s extremely helpful to have you here. It is really helpful to have questions answered. I hope the next process can involve ongoing communication. We all want to feel like this is our plan and we are behind it, because the lives of our sons and daughters are involved.

**Ricker:** There’s a way to talk where you don’t go into a cave. This meeting is on my calendar; my expectation is that Karen Mason, Gary Wolcott, or myself will be here. I would also like to have Nikki be here as well. That’s the least that you deserve and that should have happened from the beginning.

**Cullen:** That’s fantastic, thank you! (Large round of applause).

**Developmental Services Stakeholders Continuum of Care – Update**

**Cullen:** The Developmental Services Stakeholders Continuum of Care began as a group of parents who met for years with DHHS to design a better system of care. Then, the LD 1816 Workgroup merged into this group. The Stakeholders Continuum of Care group has been meeting monthly, for the most part, for the past few years. However, just this past month we received notice from OADS that they were no longer going to attend these meetings. The Department suggested that members of this group could instead participate in the Maine Developmental Services Oversight and Advisory Board (MDSOAB), but the responsibilities of that organization are different. The parents who have been involved in the Stakeholders Continuum of Care are going to continue to meet. For now, this group will act as a Steering Committee for the Coalition, and will remain focused on seeing through a Continuum of Care. As a Steering Committee, we will brainstorm potential speakers and topics for meetings as well as what information would be beneficial to the Coalition. I would welcome the idea of this group returning to its previous role as an inclusive think-tank for the Department as a Developmental Services Stakeholders Continuum of Care.

**Legislative Updates:**

**Charlene:** I am delighted to see Ricker at this meeting, and to hear from him as the meeting has progressed. I think this dialogue, as we all know, is critical. We’re at the end of a two-year legislative session. Primary elections will be held across the state tomorrow. I encourage everyone to vote. Apart from people who are no longer eligible due to term limits, members of the Legislature will be up for re-election. Between now and the November general election is the perfect time to reach out to people who are running for office, and talk with them about your issues, priorities, and concerns. They’re much more apt to listen, frankly, when they want you to vote for them. This is the time to start that outreach. Also, there is one current representative up for re-election who has already expressed interest in sponsoring a new version of LD 475, the bill Peter Stuckey introduced last session that would increase the Section 29 cap. LD 475 would be a huge step towards changing the business model, as Ricker was talking about before. If you provide enough support to families so that they can continue to work and continue to surround young people leaving the school system with natural supports, there is the higher possibility of folks not even looking towards group residential settings, but instead being able to live independently. Use of adaptive equipment and other technological advances are the things that will truly move that business model along. I hope we’ll be having those discussions and have Department support when the Legislature returns next year.

**Cullen:** So this is the time to outreach candidates, invite them over, and educate them about what you face as families, and the challanges facing your sons and daughters, so they’re informed when they’re in the position to make decisions.

**Housing Update:**

**Cullen:** At the federal level, both theSenate and House voted in THUD (Transportation-Housing and Urban Development) budgets that look remarkably similar, which finally includes an increase in HUD funding. These funding levels get us back to FY 09 levels, but it is an improvement compared to recent HUD budgets. The budgets each maintain similar levels of funding for Section 8 vouchers, and other HUD programs such as the HUD 811 program which also provides rental subsidies targeted to this population. We will see if they reach agreement and vote a budget through, but they are close which is encouraging.

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

**Cathy Register, Children’s Behavioral Health Services (CBHS):** Last time I was here I talked about the waitlist for Section 28 – we are plugging away on that. We are finding that there are a lot of duplicates on the waitlist; we are excited to tighten that up. We have two new specialized Section 28 workers – one in Augusta and one in the Portland area. For providers of children’s or adult case management, Jeanne Tondreau from OCFS has a 90-minute training on transition services that she would be happy to give for agencies. If any providers are interested, I would be happy to contact them. Additionally, we have quarterly provider meetings scheduled for late July and August.

**Cullen:** It’s nice to have both OADS and OCFS at the table today. Thank you, this is fantastic!

**Announcements:**

* *Vaxxed* is playing at Cinemagic in Westbrook for four days, from 6/17-6/20, at various different times.
* Ohio has become the first state in the nation to have their ABLE account approved.
* [Click here for the Dementia Capable Care of Adults with ID and Dementia Workshop flyer](http://www.maineparentcoalition.org/uploads/2/6/1/1/26115022/maine_2__3_day_flyer_june_2016.pdf).
* The Non-Traditional Communication Conference is on June 30, 2016, at the Cross Insurance Center in Bangor. If you have not registered but want to please contact Romy. [Click here for the conference agenda](http://www.maineparentcoalition.org/uploads/2/6/1/1/26115022/ntc_communication_conf_2016_agenda.pdf).

**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 really clear, such as transition. Our goal is to be an easily accessible information clearinghouse.

**Cullen:** At our next meeting on **July 11, 2016,** our featured speaker will be **TBD. Topic: TBD.**

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).***