March 13, 2017

Minutes

Present: Debbie Dionne, Kim Humphrey, Margaret Cardoza, Peter Stuckey, Emily Haugh, Cathy Register, Jamie Whitehouse, Staci Converse, Beth McLroie, Erin Vogel, Gil Moreno, Rich Cantz, Betsy Mahoney, Charlene Kinnelly, Todd Goodwin, Neal Meltzer, David Cowing, Laurie Raymond, Lorie Dorrance, Cullen Ryan, and Vickey Rand. Via Zoom –Sanford (Waban): Jerry Silbert and Morgan Jones. Auburn (John F. Murphy Homes): Kellie Pelletier, Ann Bentley and Darla Chafin. Winthrop (Autism Society of Maine): Maine Parent Society. Cathy Dionne. Brunswick (Independence Association): Carolyn Morse, Jeff Leonard, Ray Nagel, Lisa Wesel, and Colleen Gilliam. Gardiner (Uplift): Pam Carnie. Farmington (LEAP): Darryl Wood and Ellie Duley. Orono (Center for Community Inclusion and Disability Studies): Bonnie Robinson. Misc. sites: Stacey Lamontagne, Emily Flinkstrom, Jeanne Hackett, 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)*.*

**Cullen:** With the agenda and notification for this meeting I distributed two action alerts. One was for the upcoming OADS forums on Section 21. We are hoping they will hold a forum for the Coalition which would be an easy path for broad input. At the January Coalition meeting OADS staff presented the possibility of utilizing a Coalition meeting as an additional Section 21 forum, and holding an additional forum during the day could create more access for parents and family members, many of whom are unable to attend evening meetings. I look forward to hearing an update on this from OADS staff.

The second action alert is rather significant. The Governor’s Biennial Budget includes funding to raise the Section 29 cap, doubling the number of hours available to people being served by the Section 29 waiver. Improving Section 29 is something that the Coalition included in its Developmental Services Lifelong Continuum of Care, to create a flexible system that can meet each person where he or she is at in terms of service needs. Some, including myself, expect the doubling of the cap may solve the service needs for perhaps 80% of the 1399 people on the waiting list for Section 21 services. It might also allow a parent to work full time while a son or daughter receives support. This budget initiative also has supports for employment as something delivered outside of the cap (not counting towards the home and community support hours). Support for employment is a key focus of the Developmental Services Continuum of Care originated and supported by the Coalition. This is an excellent initiative by DHHS and having it included in the Governor’s budget is very significant. Now is the time to contact members of the Health and Human Services Committee and the Joint Standing Committee on Appropriations and Financial Affairs to offer messages of support for this portion of the Governor’s budget. ([for more information on how to contact Committee members please click here for the full action alert](http://www.maineparentcoalition.org/action-alerts.html)). You can call or send a quick email. It doesn’t have to be long and your message can be simple. This is a tremendous opportunity, for which everyone around this table has worked for a long time.

**Charlene Kinnelly:**  The Health and Human Services (HHS) Committee held a second work session last week, where they voted to include this in the budget unanimously, of all members present. Senators Hamper and Chipman were not present for the vote, but both Senators appeared supportive in previous sessions. Please thank members of the HHS Committee with your emails. Sending emails to Appropriations would be beneficial to the passage of this portion of the budget.

**Featured speakers: Betsy Mahoney, Parent. Topic: Block grants.**

**Cullen:** Today we have two speakers, the first of whom is Betsy Mahoney, a parent and long-time member of this Coalition. Betsy is here to discuss the potential ramifications of Medicaid reform that includes per capita caps or block granting, both are ways in which Congress may attempt to change Medicaid as it works to repeal and replace the Affordable Care Act (ACA).

**Betsy Mahoney:** My **s**on has been a recipient of Medicaid for years. He was lucky enough to get a Section 21 waiver back in 2011. This has been extremely helpful for him and my family for numerous reasons. Hearing about potential changes to Medicaid which would negatively affect my son along with others worried me to the point of doing some background research on potential Medicaid reform.

Even before President Trump’s inauguration, there was a plan in place to repeal the ACA; soon after inauguration day, Republicans in Congress formally began the process to do so. To me this was very disturbing news. Back in December, part of what Congressional Republicans wanted to do was turn Medicaid into a block grant program. Since then I have been self-educating regarding block grants and per capita caps. I was scheduled to give this presentation last month, when it was looking like Congress would be pursuing block granting Medicaid. However, since then they are talking about something similar – a per capita cap.

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

I discovered that the proposal to convert Medicaid to a block grant program has been on the table since about 1980. Why is Congress interested in restructuring Medicaid? It seems the biggest reason, possibly the only reason, is to reduce spending. It appears some members of Congress want to save money on healthcare costs to pay for tax cuts. Since discussion began about repealing and replacing the ACA, different ideas have been floating around; last week, Speaker Paul Ryan introduced a House bill, the American Health Care Act (AHCA), which proposes a per capita cap for Medicaid. It is worth noting that there is a lot of opposition to this bill, even among Republicans; however, it’s worth addressing because this bill is on the table in the House. A cornerstone of the Republican party is its interest in states’ rights. There are a lot of states that won’t be happy about this proposal, as they’ll have a lot less money to work with. There are individual Republican governors who have spoken out in opposition to this bill – some because they govern Medicaid expansion states, and others because they feel it doesn’t go far enough.

**Discussion:**

-It was stated that Governor LePage expressed caution about this plan, specifically with its effect on the elderly.

**Betsy:** Some members of Congress are aiming to pass this through the budget reconciliation process. It appears that there’s already a lot of opposition within the Republican ranks, and there are other proposals being floated that would restructure and/or cut Medicaid. Senator Susan Collins is pivotal to this process. Senator Collins voted to approve a budget blueprint which was the first step in repealing the ACA; however, she has been adamant that repealing the ACA without a suitable replacement is ill advised. Senators Collins and Cassidy released their own plan to replace the ACA, which would rely heavily on a new type of Health Savings Accounts (HSAs).

**Charlene:** It would be much simpler if this was “The Republican Plan.” This is Speaker Ryan’s House Republican plan; we don’t yet know how the Senate Republicans will react to it. The President is also in the mix. In terms of the budget reconciliation process, it’s a mess and completely political. Anything can become a matter for reconciliation if there’s a strong enough party will to do so. It’s not going as fast as Paul Ryan would have you believe, but it absolutely is a clear threat.

-It was stated that not too long ago, Commissioner Mayhew sent a letter to Health and Human Services Secretary Price urging conversion to a block grant.

-It was stated that a lot of the in-party opposition is that Speaker Ryan’s plan is still too generous.

-It was stated that with a per capita cap, people are moved into five categories, with each category being capped; however, the state doesn’t have to deploy funding up to the cap, it can utilize less.

**Laurie Raymond**: There is a group going to a disability conference next week in Washington, D.C. We’re having breakfast with both Senators Collins and King. It might be advantageous to deliver a letter from the Coalition on this.

**Cullen:** To do this, we would need a vote from the Coalition to send a letter with specific language stating a position.

-A motion was made and seconded to draft a letter to Senators Collins and King regarding Medicaid reform saying the Coalition is opposed to a per capita cap for Medicaid, and have it be delivered in person by Laurie Raymond.

Discussion: It was asked if members of the Coalition would be able to look at the letter before it is disseminated. It was stated that the group needs to come up with simple language, on which everyone can agree, as logistically it would be very difficult to circulate a draft of the letter. The group provided suggestions for draft language for the letter:

* “Oppose efforts to slash Medicaid and restructure it into a per capita cap or block grant.”
* “To maintain Medicaid as an entitlement program.”
* “To ensure an appropriate array of services, no more no less. Have Medicaid remain an entitlement program and oppose cuts to the program.”

-It was stated that accentuating the positive would be beneficial, as well as highlighting that it’s ultimately important to ensure that people have the services they need – we don’t want to go backward.

-After discussion, the group voted unanimously to send a letter on behalf of the Coalition capturing the above-noted sentiments.

**Cullen:** I want to thank Betsy for her presentation, well done!

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

**Featured speakers: Charlene Kinnelly. Topic: Legislature 101.**

**Cullen:** Charlene Kinnelly is our foremost expert on the ID/DD service world, having more than 50 years’ experience (beginning in 1966). She has provided two other excellent presentations to the Coalition, which can be found on the website ([click here](http://www.maineparentcoalition.org/how-the-system-works.html)). Today, she is here to provide an overview of the Legislature and how bills become law in Maine.

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

**Charlene:** Every Committee has a Committee Analyst, a professional (very often an attorney) whose job it is to analyze the laws and advise the Committee not about the content, but about if the goal is “X” than the language needed to achieve that goal is “Y.” There is clerical support staff in each committee as well. Committees carry status with their colleagues. When committees have dealt with a bill, other members of the two chambers will often defer to the opinions of those subject experts.

There are two kinds of bills. The first is an “act,” which literally changes the language in a statute. Then there are “resolves,” which are bills that would become law but don’t change the law books themselves. Representative Stuckey introduced a bill several years ago to direct the Department to gather stakeholders together to look at future system redesign; this was at the time the Coalition was working on its White Paper. This was a resolve because it wasn’t changing the law book itself.

**Discussion:**

-It was asked how the APA (Administrative Procedures Act) process can be changed. It was stated that recently the Department’s rule making process doesn’t feel very democratic.

**Staci Converse:** This procedure is outlined in statute (Title 5). If part of that process is deficient, it would have to go to the Legislature to change the law; then the Attorney General’s office would implement that law.

**Charlene:** A lot of people believe that the Attorney General (AG) has the power. However, it’s the AG’s job to advise the Executive Branch and/or legislators about laws. It terms of the APA process, it’s the Executive branch that is responsible for rule making. The AG has advised, presumably, DHHS not to talk about rules during the rule making process, but it’s not the AG that needs to be involved in changes to the process. If you look at APA rulemaking across Maine government, the amount of communication while the rule making process is underway varies widely.

-It was stated that whether there is discussion with the Departments during the rule making process is political.

-It was added that per Maine State statute, 100 Maine citizens can petition the Legislature to get involved with rulemaking as well. Or, someone directly affected by the rule can petition the Legislature for legislative review of a rule. That petition goes to the committee that has jurisdiction. One-third of that committee would have to agree to open it up to public comment. This procedure has been utilized very few times over the last number of years.

**Cullen:** Charlene,I want to thank you for this informative presentation! To have this all in one place as a succinct summary is outstanding. Thank you!

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

**DHHS Updates:**

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

**Cullen:** Staff from OADS are unable to attend today’s meeting. I don’t have any information from OADS. Does anyone else?

**Neal Meltzer:** I have some good news to share. Last fall the Department unveiled proposed rules for Section 21. Changes to the reimbursement rate and the elimination of the billing range were included within this proposal. This was a key component to which many testified in opposition at the public hearing, stating that for providers who are already struggling these changes would prove to be extremely detrimental. The Department released the final adopted rule at the beginning of the month. Due to the feedback received during the rulemaking process, from people in this room and many others, that piece of the rule was removed. In recent history, it’s very uncommon for feedback to have that kind of effect. DHHS initially was adamant that removing the range way key to its proposed rule change. This is evidence that all the efforts around this table do matter; DHHS heard our concerns and responded appropriately. It’s important to give credit where credit is due. With that said, there’s always something else. I’ve heard parents eloquently state the challenges of not having consistent staffing. Providers talk about hiring and retention challenges. I was taken by the discussion regarding Section 29 and funding in the Governor’s budget to increase the cap. Should that come to fruition, and it would be a wonderful thing, people would likely sit there; they wouldn’t receive services because providers don’t have the staffing capacity. Agencies can barely staff their programs currently. It’s our duty to provide services to people to keep them safe, never mind providing the consistency for them to truly succeed. We’re in a workforce crisis and this underpins the entire system of care. To help address this, “LD 967 – An Act To Ensure Access to Community Services for Persons with Intellectual Disabilities or Autism” has been introduced as an emergency bill by Representative Herbig. This bill would return the rate of reimbursement back to the inflation-adjusted 2007 rate. The rate that providers are paid was established in 2007 by a 2006 cost study. Since then, the rate has been reduced by over 12% through cuts; when you factor in inflation it’s effectively a 30% rate reduction. A lot of this has come on the backs of our DSPs (Direct Support Professionals); their wages aren’t competitive. The increase to the minimum wage, which is needed, unfortunately compounds the problem. This bill would use the 2007 rate, that the Department agreed on, the Legislature approved, and was picked by actuaries – and adjust it for inflation. Part of this bill is also ensuring that the rate increase goes to staff, versus administrative costs. This would enable providers to raise their wages, broaden the gap between wages paid for this work and minimum wage jobs, and provide a stable foundation for this essential system of care. So far the bill has received great support from the HHS Committee and the Joint Standing Committee on Appropriations and Financial Affairs. I ask that if you feel inclined to support this to consider making it an action alert when a public hearing is scheduled.

**Cullen:** This will be captured in the minutes and we will watch the bill to inform people of the hearing

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

**Cathy Register:**  We have some upcoming events:

* [Looking at Employment with New Eyes: Creating a Culture of Work for Youth with Disabilities, on 3/29 (Bangor) and 3/30 (Auburn)](http://www.maineparentcoalition.org/postings.html).
* DHHS is partnering with MaineHousing to host a “Statewide Youth Homeless Strategic Planning Meeting” with a focus on ending youth homelessness in Maine. The meeting is scheduled for 5/12 at the Augusta Armory from 12:30 pm to 4:30 pm. For more information contact Cathy Register at 822-2331 or [cathy.register@maine.gov](mailto:cathy.register@maine.gov).

*(*[*Click here for the full update from Children’s Behavioral Health Services*](http://www.maineparentcoalition.org/uploads/2/6/1/1/26115022/cbhs_updates_for_march_2017.pdf)*)*

**Housing and other Updates:**

**Cullen:** The Administration leaked that President Trump is considering a $6.6 billion – or 14% – 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 hasn’t been released formally, it is quite significant. There is a lot to watch on the federal level.

**Staci Converse – Disability Rights Maine (DRM):** We are actively working on supported decision making. We’re working on a pilot project at Mobius, where four individuals are trying out supported decision making. We’re speaking to three DHHS district offices next week, working with individual clients, and meeting with OADS leadership. Margaret is helping with videos about people’s experiences with supported decision making.

**Margaret Cardoza:** We’re also meeting with DHHS case workers to help with the transition in their role as state guardians regarding supported decision making.

**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 see where that goes and bring suggestions 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 **April 10,** **2017**.

**Featured speakers: Bo Bigelow, Author and parent. Topic: Disability activism.**

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).***