July 11, 2016

Minutes

Present: J. Richardson Collins, Joan Rogers, Margaret Cardoza, Staci Converse, David Lawrence, Dina Martinez, Peter Stuckey, Cathy Register, Christine Campbell, Megan Meehan, Michael Foster, Patrick Moore, Sally Mileson, Julie Brenna, Jamie Whitehouse, Debra Olmstead, Rachel Dyer, David Unger, Jennifer Putnam, Ed & Suellen Doggett, Mary Chris Semrow, Liz Weaver, David Cowing, Laurie Raymond, Cullen Ryan, and Vickey Rand. Via Zoom – Bangor (UCPofME): Andrew Cassidy, Bonnie Robinson, and Jon McGovern. Sanford (Waban): Morgan Jones. Auburn (John F. Murphy Homes): Darla Chafin and Ann Bentley. Gardiner (UpLift): Charlene Kinnelly. Winthrop (Autism Society of Maine): Cathy Dionne and Glenda Wilson. Westbrook (Woodford Family Services): Stacy Lamontagne.

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)*.*

**Featured speaker: Nicole Rooney, Manager, Special Projects, DHHS Office of Aging and Disability Services (OADS).** [**www.maine.gov/dhhs/oads**](http://www.maine.gov/dhhs/oads) **Topic: Olmstead Update – A review of Maine’s Olmstead Plan, progress made, and what comes next.**

**Cullen:** Ricker Hamilton joined us last month and commented that Nicole Rooney would be well poised to present on Maine’s Olmstead Plan. The Olmstead Act came out in 1999 and is a pivotal piece of legislation that has moved us forward as a society, away from institutionalization and towards community inclusion.We are pleased to have Nicole here to present on Maine’s Olmstead Plan.

**Nicole Rooney:** Thank you for having me. We have been fortunate to have a consultant on contract with us for almost two years now who is our Maine Olmstead expert. As Cullen reminded us all, Olmstead was a 1999 Supreme Court decision. When I think of Olmstead, I think of it as a core value we all need to embrace. The federal government has continued to support that decision with initiatives such as the new HCBS (Home and Community Based Services) settings rule.

**Begin Presentation.** [**Click here for the presentation**](http://www.maineparentcoalition.org/july-2016-presentation.html)**.**

**Nicole:** We heard feedback that the Olmstead Roadmap was a very large, cumbersome document. We wanted to make sure that the progress report was much more tangible, easier to understand, and didn’t simply sit on a shelf. The report is available on our website ([*click here*](http://www.maine.gov/dhhs/oads/trainings-resources/initiatives/olmstead.html)) and includes a lot of information including survey responses; it also includes a summary of a seven-session public forum we held last June and August. We went out into the community with this plan highlighting these objectives and received about 70 comments during the public comment period; we are in the process of finalizing the draft as a result of those comments. The Department has committed to staying with our consultant to ensure that this is a living, breathing document. This spring we held Maine’s first Community First Conference, where we highlighted Olmstead, solicited feedback, and brainstormed ways to best evaluate the plan’s success. Though we’re no longer in the formal public comment period, it doesn’t mean the book is closed on those conversations. We want to ensure that these conversations are still occurring. If you have ideas or thoughts on this, please email me ([Nicole.Rooney@maine.gov](mailto:Nicole.rooney@maine.gov)). We may not be able to change the document, but this feedback could become part of the strategies we’re developing. We approached the Olmstead public forums very conversationally. We do want to hear from you and how we can improve things.

**Discussion:**

-It was stated that this was one of the rare times where it was explicitly clear that comments and further input were considered, and the content was clearly amended reflecting input received across different venues. That was very nice to see and was very appreciated. It was suggested that the Coalition be used as another forum to solicit future feedback regarding Maine’s Olmstead Plan.

**Nicole:** Our consultant will be coming here a few times per year. Maybe next time she’s scheduled to visit she could attend this meeting. If you haven’t had the opportunity to read the progress report, you will see some very real comments on where we’ve succeeded, but we were also very honest regarding what is still left to do. If people took the time to provide feedback, we wanted to make sure it was reflected in this document.

-Attendees expressed thanks for the Department’s very thorough process. It was stated that there are still a few areas of concern, specifically regarding what, if anything, is being done to monitor deinstitutionalization and whether or not nursing homes are taking people for whom a nursing home is not an appropriate setting. It was asked if a preventative measurement could be considered. It was suggested that an ombudsman would be able to provide direct feedback regarding this

**Nicole:** That’s a really good question about monitoring and prevention – that is certainly something to be considered.

**-**It was stated that monitoring the death rate, monitoring how many people are dying and not getting services, is important.

**Karen Mason:** In terms of people passing away, the Department has reinitiated a mortality review process, which went by the wayside a few years back. When someone served by OADS passes away case managers are required to create a report, and then we have a nurse in our office who reviews all deaths. When there are further questions that person will bring it to the appropriate program manager. That’s not to say that the death is “investigated,” however we know that we need to re-craft how we monitor deaths to see if any trends emerge. There was a study a few years ago that found that the actual beds purchased for nursing homes were slippery, which in turn caused the sheets slip off and people to fall out of bed; people were getting hurt. This study initiated an entire systems change.

In terms of folks with ID/DD in nursing facilities – the facility has to do an assessment to ensure that the person going into the facility receives services unique to meet his or her needs; this is then monitored on a regular basis. On top of this, in order to be eligible for a nursing facility one would have to meet the facility’s standards as well. If you know of someone who wants to leave a nursing facility, there are reserved slots in Section 21 to accommodate this.

-It was stated that it is imperative for there to be an interlocking relationship between the Department and standard medical care. Co-morbid diagnoses among those with ID/DD is a major gap that’s not being filled.

-It was asked how the Section 21 waiver application to CMS ([Centers for Medicare and Medicaid Services](https://www.cms.gov/)) intersects with the work being done with Olmstead, and if one informs the other.

**Karen:** They inform each other in terms of the guiding principles, but there is no direct intersection between the two. It’s CMS’ tenet that we always look to provide services and supports that help people become as independent as possible, and hopefully stay out of institutional settings – that’s what the waivers are for. So in terms of that, it coincides nicely.

-It was stated that different parts of the Department sometimes appear to be on different tracks, when to someone on the outside it seems that the work being done is quite similar. It was stated that it makes sense to bring Olmstead to the table when planning for the waivers and have it inform the process.

**Karen:** We will certainly bring Maine’s Olmstead Plan to the table when planning for the waivers. We always try to bring various projects and voices, such as other offices, to the table that would inform the work we’re doing.

**Nicole:** We had a two-day intensive planning session to develop the Olmstead objectives with the other DHHS offices. Some of the other offices didn’t have the same level of knowledge so it was a very informative process. There were a lot of program people, people on the front lines, who were part of the planning – it was truly an organic conversation even from the State perspective. When we were developing these objectives we looked at the strategic plans across all of the departments involved to make sure they were cohesive. We’re trying to make sure we’re not doing this in a vacuum.

-It was stated that it would be beneficial to move to person-centric language – for instance moving from “as independent as possible” to “as independent as desirable” when discussing living options. For some, having independence as the zenith lends to fear and isolation. Someone may physically be able to live independently, but he or she may not want to because of the possibility of loneliness and isolation.

**Karen:** There are always these push-pull points. The mandate is for people to be involved in the community. Providers are there to help people create that community and increase their abilities. This interdependence requires a balance.

-It was stated that it is sometimes difficult to talk about choice, because in reality it boils down to funding. It was stated that a person can only choose what is paid for; true choice would be different.

**Karen:** The money does only go so far, and the goal is also to build a natural support system that will carry someone the rest of the way. You and I make decisions based on a lot of factors, our incomes being one of them. If I can’t afford something I figure out what can be done to achieve it. Can I do favors for my friends and have them pitch in in return? This is an example of the natural supports we’re looking to build.

-It was stated, respectfully, that there are also ways in which the funding mechanisms restrict doing just that – the funding restricts staff from building those natural support systems. It was stated that this group needs to figure out how to change that, so that the right supports are there at the right time, and have the flexibility for them to ebb and flow as needed.

**Representative Peter Stuckey:** Last winter, when we held the public hearing on the SIS (Supports Intensity Scale) rule, I listened very carefully to the testimony delivered. At the end of the day numerous people testified, all in opposition. There wasn’t one person who came out and said “spot on.” I understand there were even more written comments. I then sat in a room and listened to the final rules that were presented as a result of the public hearing and comments received by the Department; I wasn’t encouraged because the final rule did not reflect what I heard in that process. I’m listening to a similar process now and I want to be optimistic. It really surprised a lot of people in this room when the final rule came out; up until that point we knew it wouldn’t be perfect, but we had high hopes and we thought we knew the direction it was going. It was apparent that it was a broken process and it took an extraordinary measure to right it. People expect a different feel to the Olmstead process as it moves forward.

**Nicole:** I wasn’t part of the SIS process, but I can say that we believe this process will have a different outcome. I think we tried to approach this in a very pragmatic way, as evidenced by our engaging internal sponsors across department offices, the community forums, and how we continue to provide education and take feedback. We approached this process a little more methodically than we have before. Also, I think it speaks volumes that we didn’t try to do this with our own staff and instead brought a third-party consultant on board. We have taken comments seriously and addressed them in the progress report. Our hope is for this feedback loop to continue. We’re also committed to having an evaluation plan, that we’re going to check in on quarterly and share publicly.

-It was stated that it would be beneficial for the larger community, including the Legislature, to be able to weigh in on what we want versus what we can actually do. At the end of the day that’s a societal choice and it’s not any one chair at the table’s responsibility to make alone. With the Consent Decree there was a big public discussion about what ought to be in place – it’s at that level where this work needs to be done.

**Karen:** We had a lot of public comment and feedback. The Olmstead process is very different from the process for the Medicaid waivers.

**Cullen:** The goal of these presentations is for us to learn and have an interactive dialogue, which we certainly accomplished today. I am very encouraged by your inclusive language and that you’re seeking input from us – I heard that very loud and clear. Thank you for that, and thank you for being here today!

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

**DHHS Update:**

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

**Cullen:** It is a pleasure to have Karen Mason here today, and it was wonderful to have Ricker at last month’s meeting. My son was nine when we started this Coalition, and he’s twenty years old now. As a result of all of us working together, instead of falling off a cliff when he turned a certain age, my son is benefitting from transitioning from Section 28 to Section 29 services, which is now very similar to Section 21 in terms of being comprehensive. He has adult services before he ages out of school. This is huge, and a wonderful example of the success of the efforts of this entire group.

**Karen Mason, Associate Director, OADS, DHHS:** Nicole referenced the HCBS community settings rule, which was also discussed at this meeting last month. Last month’s conversation included information on a pilot project that some providers we’re keyed into which included survey questions to take the next step in terms of compliance. We submitted our Transition Plan and CMS came back to us with some clarifying questions, and [Office of MaineCare Services](http://www.maine.gov/dhhs/oms/) (OMS) responded. At this point in time we’re going to put the HCBS stakeholder process on hold until we receive approval from CMS on our Transition Plan. People who were involved in the process have been notified. Right now we’re in a holding pattern. We’re hoping our plan will be approved; CMS indicated that the plan looked really good.

-It was stated that other states have received conditional approval, and had to complete tasks similar to the survey that was underway in Maine. It was asked if the Department is anticipating provisional approval, and if that is why the process is now on hold.

**Karen:** The process is on hold because we want to make sure our next step is the right next step. We’re not getting any sense at all whether or not we’ll get conditional approval.

**Karen:** Relatedly, the Person Centered Planning (PCP) manual has been in draft form for a while. However, before we send that out we wanted to make sure that the PCP provisions from the HCBS settings rule, especially having the person be the driver of the plan, are incorporated in the manual. We’re hoping to have it up on the website within a few weeks.

-It was suggested that SUFU ([Speaking Up For Us](http://sufumaine.org/)) or individuals with expertise in running their own PCP meetings provide feedback.

**Karen:** This is a good idea.SUFU created a PCP training video that is also very informative ([*click here for the video*](http://sufumaine.org/blog/what-to-expect-at-my-pcp-meeting/)). I also wanted to thank everyone who participated in the family forums; approximately 150 families and individuals participated, which is fantastic. Nikki Busmanis, Lebrun Joseph, and Jen Fales are working on a communications strategy based on input from those forums regarding how the Department disseminates information, to better enable people to understand a very complicated process and system. Some of the ideas included email blasts, YouTube videos, call-ins, and webinars.

**Cullen:** At the Portland forum I mentionedhaving the Department take advantage of the Maine Coalition for Housing and Quality Services as a vehicle for delivering information and soliciting feedback. The Coalition’s email list reaches a vast and broad array of people across the entire state – some 4,000 people – and the website is constantly updated and acts as an information clearing house so people can easily access information and resources. I hope the Department takes us up on our offer.

**Karen:** Yes, absolutely.

**Waitlist Numbers as of 6/30/16:** Section 21 – 1264, Priority 1 – 0, Priority 2 – 385, Priority 3 – 879. Section 29 – 0.

**Karen:** Regarding Section 29,there isn’t a waitlist currently, but it does take some time to make offers because we only have one Waiver Manager managing two waivers. Currently it takes about three months for her to get through the list to make offers. I have heard rumors circulating that the Department isn’t making Priority 1 offers and that no one is reaching the level of vulnerability necessary to be categorized as Priority 1. This is not accurate information. Unfortunately, people do experience abuse, neglect, and exploitation; if they’re on the waitlist we make those offers immediately.

I have requested information from Emily Kalafarski, our Waiver Manager, regarding how many people reached Priority 1 and were offered services in the last year. We couldn’t put those numbers together before this meetings – but we’re thinking 30 or so in this past year. All 200 offers that were included in the budget have been made; offers started back in December and Emily made the last offers about a week ago. Approximately 57% of people who received offers have started receiving waiver services. Right now we’re in the process of doing some forecasting. Typically, in the past we’ve made about five offers per month, based on attrition. We need to look at the finances and the numbers we’ve put in the waiver application. We’ve talked about using methodology for Priority 2 as a standard practice. In making these offers, we discovered a small number (about 30 or so at last count) of folks who had moved out of state, no longer wished to receive the service, or that we were not able to locate. Moving forward, we’re going to look to a process where we reach out to people or they reach out to us about whether people want to remain on the waitlist, because we want to make sure people completely understand the decision before they come off the waitlist.

When we originally received the funding to take 200 people off of the waitlist there were 400 people; now that number is 385 after making the offers. People apply for the service all the time. We can bring those numbers next month. We started to research how many people apply for Developmental Services and found that the number increases every year. This year we received approximately 400 applications, and the vast majority of the people who apply are determined eligible. The numbers continue to build up.

-It was asked how many people come off the children’s waivers each year. It was stated that this information would be beneficial for planning purposes.

**Karen:** We do have those numbers I just don’t have the information on hand. I’ll be sure to include that information for the next meeting. There are people who come off the children’s waiver each year, but we also receive applications from 60-year old adults, with 80 to 90 year-old parents, who are just entering the system for the first time.

-If was asked how the Department makes offers for Section 21, what criteria is used, because how long someone has been on the waitlist doesn’t appear to play into it.

**Karen:** A lot of this isdriven by rule, and the definitions for Priorities 1, 2, and 3. In rule, it states that you have to look at everyone within that category when making funding offers. We discovered that there were people who had been on the Priority 2 waitlist for years; when we went to determine how best to make offers we first had to figure out how we could find the most up-to-date information for those on the waitlist. Based on that criteria we created a one-page questionnaire and everyone in the Priority 2 category, as best we could, were called and that’s where we received responses such as “I don’t know what you’re taking about, I don’t need services.” Others gave really great, updated information which was very useful in determining offers. There were some great scenarios where Emily spoke to the individual and the individual answered most of the questions him or herself. It was clear through that process that there were people who were more medically vulnerable, had intense behavioral challenges, and so on that hadn’t been disclosed prior to this process. It was a wonderful and very informative process. There was then a scoring system based on the questionnaire. It was comforting to discover that the top 20 people on our radar really were the folks that landed in the top 20 through the scoring process. We’re looking to incorporate those questions into the overall application process. The current process lends itself to more narrative, whereas we need more direct information as to what’s going on every day.

**Cullen:** Thank you for being here, Karen, and thank you for this informative update!

**Legislative Updates:**

**Cullen:** With the Legislature out of session, it is a great time to meet with your state legislators, have them over to your house, and educate them on your son or daughter’s needs.

**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 sound very good, but in actuality 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 before they recess for the summer, which is scheduled for the end of this week. The alternative would be a continuing resolution in the fall which would fund likely fund the government through the election.

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

**Cathy Register, Children’s Behavioral Health Services (CBHS):** For the past few months I have been reporting on changes with the waitlists. As of July 1st, APS initiated thenew Section 65 and 28 waitlists for kids. After the first week, the response was overwhelming; approximately 18 kids, many of whom had been on the waitlist the longest, were picked up by providers across the state. The idea is for kids to be matched to providers based on the date of their referral to the service, based on the number of days they have been waiting, versus being hand-picked by an agency. Families can still be on a specialized waitlist and request a preferred provider (or not to work with a particular provider), while also being on the regular Section 28 waitlist. If someone is called by an agency from the regular list, they have the option to accept the service and still remain on the specialized waitlist. After 120 days the Resource Unit will take over managing the waitlist. We’re very excited.

**Announcements/handouts:**

* [Specialized Housing, Inc. Program Overview](http://www.maineparentcoalition.org/july-2016-presentation.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. 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 **August 8, 2016,** our featured speaker will be **David Unger, Executive Director, Speaking Up For Us (SUFU)**. **Topic: SUFU strategic plan and employment volunteers.**

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).***