October 17, 2016

Minutes

Present: Ed & Suellen Doggett, Frances Ryan, Kathy Adams, Ricker Hamilton, Jennifer Putnam, Janet Rancourt, Joan Rogers, Glenda Wilson, Megan Meehan, Jodi Benvie, Tiffany Perry, Amy Stanley, Todd Goodwin, Debra & Kailen Olmstead, Julie Brennan, Gil Moreno, Sue Murphy, Barry Schklair, Jamie Whitehouse, Richard Norton, Cathy Register, Staci Converse, Rachel Dyer, David Lawrence, Luann Lawlor, Rob Lawlor, John Regan, Margaret Cardoza, Romy Spitz, Jerry Silbert, Representative Peter Stuckey, Neal Meltzer, Arthur P. Clum, Betsy Mahoney, Rebekah McIntyre, Kim Humphrey, Debbie Dionne, David Cowing, Lenny Gulino, Charlene Kinnelly, Beth MyLroie, Maura McDermott, Cullen Ryan, and Vickey Rand. Via Zoom – Bangor (UCPofME): Andrew Cassidy, Lynn Faerber, Bryce Kennedy, and Justine Kennedy. Sanford (Waban): Morgan Jones. Biddeford (Community Partners, Inc.): Meg Dexter. Auburn (John F. Murphy Homes): Darla Chafin and Ann Bentley. Winthrop (Autism Society of Maine): Cathy Dionne and two ASM staff. Gardiner (Uplift): Heidi Mansir. Orono (Center for Community Inclusion and Disability Studies): Bonnie Robinson, and Fran and Dick Neubauer. Misc. sites: J. Richardson Collins, Alan Kurtz, and 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: Neal Meltzer, Executive Director, Waban.** [**www.waban.org**](http://www.waban.org/) **Topic: Details and discussion regarding the proposed rule changes for Section 21 and Section 29 – how this may affect you and your family.**

**Cullen:** We learned about upcoming proposed rule changes for Section 21 back in August when the Department presented a high-level overview of what those proposed rule changes would involve *(*[*click here for the August meeting minutes*](http://www.maineparentcoalition.org/uploads/2/6/1/1/26115022/minutes_-_maine_coalition_for_housing_and_quality_services_8.8.16.pdf)*).* When the rules were put out and examined by folks, additional details appeared to emerge that seemed to create worry among some. We made this today’s topic so that we could examine and discuss the proposed rule changes in more detail. Neal Meltzer has gone through the proposed rule changes and examined them carefully. There are Public Hearings this Wednesday, 10/19 in Augusta covering the proposed rule changes for Section 21 and Section 29. ([*Click here for more information on the public hearings*](http://www.maineparentcoalition.org/public-hearing-information.html)). We as a Coalition have been trying to work with the Department to be included in the rule making process from inception to when they are formally presented so we can all be on the same page, and so we don’t find out about important information after the fact, which can be stressful. Once the proposed rule changes are posted the Department cannot address them, which leaves no room for open dialogue.

**Neal Meltzer**: As I was thinking about this meeting I thought back to ten years ago when the Coalition first came together. It’s a testament to this group that you continue to be an effective mechanism for people trying to work to make a better system of care. This group has also done the work – it created the White Paper looking at long term system changes that from the Coalition’s perspective needed to be addressed. This is very significant. A parent’s commitment is lifelong, and there are many providers who have been around for a long time and continue to do the work necessary to provide the services to those who need them. Similarly, on DHHS’ side, there are many dedicated individuals who have worked for many years to create and build a system of care. Oftentimes the information Department staff has is different from that of parents and providers, which is why working together is what will build a better system. The Department may also have issues and problems that we likely have no sense of, which factors into decision making. We need a “three-legged stool,” with parents, providers, and DHHS, because a two-legged stool wobbles, and a one-legged stool falls down.

There are aspects of the Section 21 proposal that on the surface seem to make a lot of sense, such as establishing a Clinical Review Team (CRT) and addressing each person’s needs as outlined in their Person Centered Plan (PCP) – these make sense on the surface for sure. Additionally, it’s good to see the message from last year about the importance of the PCP has gotten some traction. Another aspect that on the surface makes sense are background checks for staff. A variety of background checks are done now; most are required by contract with DHHS. Conceptually these are all good things. However, if you scratch beneath the surface a little bit there are details within the 169 pages that paint a slightly different picture. I’ll talk first about ensuring that providers are staffing consistently with what they’re paid.

With the proposed rule it appears that providers will get paid for what they do, and not what they don’t. This makes sense on the surface. However, the payment structure we currently have was part of a comprehensive and integrated system that provided a range of hours that could be provided (92.5-100%) and still earn full payment – which was very specific to residential services. Why is this the case? 24/7 group homes are very dynamic environments. These are people’s lives. You put together three, four, maybe five unrelated adults living together with different needs and wants, and it’s very difficult to determine exactly how to address those persons’ needs at any one point in time. As parents you’re responsible 24 hours a day for your child, but sometimes a child sleeps, he or she may have irregular sleeping pattern, or may wake up in the middle of the night, but you’re still there. The range provides the capacity to be able to navigate the true aspects of residential life and be prepared for what might happen; so when your adult child who lives in a group home wakes up in the middle of the night with a fever and can’t explain what’s troubling him or her, there will be a provider there. The range makes sure that this can occur. Having a range isn’t unique to Section 21 residential services. There are hundreds of Medicaid reimbursed services that use a range – case management, therapists, and physicians bill based off of units. There are residential-like settings that use a range, such as long-term support and nursing homes; if the individual is in his or her bed at midnight the provider of that service gets paid for the full day – that’s a range. The current range in Section 21 is used in a variety of settings. Since 2007, when the rate was initially set, the rate itself has been reduced 11%; when you factor in inflation the actual reduction is 23%. What does that mean? Effectively providers get paid $0.77 for every $1 of support they provide. How can they do that? It hasn’t been easy. Providers have had to find ways to provide services differently, leverage technology, get more efficient, and demand more accountability from managers and direct support providers (DSPs). Those DSPs have borne some of the burden of the reduced reimbursement. DSPs are the heart and soul of the services we provide. One of the things I hear, and I’ve heard for the past ten years, is that people are concerned about staff turnover. Why does staff turnover so much? The decreasing rates are part of the issue. One of the ways providers have been able to make that work is not raising the pay of DSPs – this has not been by choice, there’s simply no other way. That directly affects retention, turnover, and people’s willingness to take on this very important but difficult work.

The Legislature recognized that there was a tremendous issue with the rate for Home Health Aides, which is a similar service. The rate they had been working under was ten years old, providers were in crisis trying to fill positions, which were underpaid. The Legislature increased this rate by more than 60%, and made sure that the increase went to the right place – by mandating that more than 80% of that increase go to wages. Voters have the opportunity in November to make a decision about what the minimum wage should be in Maine. I have strong opinions about that; I believe everyone should have a workable, livable wage. But, as the minimum wage increases and providers are not able to raise their rates of pay to try to compete, the staffing issues providers have now will get tremendously worse. However, it goes even deeper than that. As proposed, one of these proposals relative to Section 21 would remove the rate range. Removing this range would effectively result in up to an additional 7.5% reduction in funding, on top of the 23% reduction that’s already in place. Quite frankly there are very few 24/7 group home providers who will be able to navigate that. Those are just the facts. We’ve looked at our numbers over the years to determine what it would look like if the range had not been in place. This was a good exercise to understand the impact. Year after year all of Waban’s 25 residential programs would have been significantly in the red. As a mission-focused organization, Waban, and many other organizations, exists to provide services – it’s why we formed 50 years ago and why we exist today. An agency can’t provide services if year, after year, after year they can’t pay their bills. It’s that simple. For those reasons, this aspect of the proposal is worrying and I think it does truly threaten residential services as they exist today.

**Discussion:**

-It was asked if the removal of the rate range was in a specific section in the proposed rule changes, so that it could be noted in written comments and public testimony.

**Neal:** The removal of the range is addressed in the Chapter III, Section 21 proposal, specifically the removal of the range in Appendix 2a and Appendix 2b.

-It was stated that if an agency provides 88% of services on a given day, they don’t get reimbursed at 88% of the rate, they get reimbursed at a lower rate. It was stated that this doesn’t seem fair.

**Neal:** This is getting into the weeds and not directly relevant, but to your point if you don’t provide the minimum amount of service deemed necessary there is a penalty and you get paid slightly less.

-A parent stated that for parents considering testifying, rather than getting into the weeds and intricate details of the proposal, it might be helpful to talk about experiences, such as the staff turnover in your sons’ and daughters’ homes.

**Neal:** It’s always good to speak to what you directly experience. The Legislature deemed it necessary to make changes to the Home Health Aides and this is very similar. This issue and the need to raise the rate to where it’s supposed to be is directly related to ensuring the health, safety, and quality of life of the people you care about.

-A parent stated that there were some slight changes that affected staff for her son. Originally it was thought that the changes would be minor; however, these changes turned out to be a big deal. With childcare costs that many staff require, the majority of the DSPs working full time had second or third jobs. With the changes they had to adjust shifts at their other jobs, many of which provided their health benefits, or leave in order to maintain their other jobs. It was asked how many DSPs need to maintain second jobs in order to get by.

- It was stated that this system doesn’t operate in a vacuum, there are other aspects that contribute to this crisis. The Department of Labor (DOL) changes regarding salary and exempt workers also comes into play. With difficulty filling DSP positions, managers often step in to assist with open shifts. When the new DOL rules regarding exempt staff take effect these managers will have to be paid for any time they work overtime, the cost for which is substantial. Health insurance costs are also factors. With the Affordable Care Act (ACA), there is a certain level of health insurance coverage that agencies must offer, which is an additional cost. Additionally, there used to be a behavioral support add-on. People are having a hard time finding residential support for their family members with high behavioral needs because providers can’t afford to provide support for these needs anymore.

-A number of months ago this group spent time talking about the Community Settings Rule, the State’s Transition Plan, and the need for everyone to work together to build a better service system. That is going to be a herculean effort, and one that requires money. The State put forth a good effort in its Transition Plan, but this adds an additional burden. The principle core to the Community Settings Rule is client choice. When you start talking about this particular service and consumer choice it leads to staffing questions. There’s a lot happening here.

-It was stated that from a parent perspective, if the range is eliminated it will have a chilling effect on families, driving a wedge between families and agencies. If a family member wants to pick up his or her child in the middle of a staff person’s shift, that person will not get paid for the time the client is with his or her family.

**Representative Peter Stuckey:** I’m trying to figure out the rationale behind the changes and I can’t come to anything. I seem to remember being headed towards a system where people got the services they needed, no more and no less. The last couple of meetings I’ve been to it appears that people don’t understand things, at best, or they’re afraid of what the changes will mean for their loved ones. Giving everyone what they need, no more and no less, doesn’t seem to be the prevailing theme. I’m trying to figure out where it got off-track and why. At one point it felt like the Department, providers, and consumers where gathered around a White Paper that laid out a system that tried to address the age of the current methodology of paying for these services. A lot of work got done in a shared way over a period of time, and I was expecting that what would get rolled out would have been on the same page with this work. I’m trying to understand where and why it got off track because it doesn’t feel that there’s this same kind of “we’re all in this together” mentality. This has to work for everybody. As someone who was trying to put in place the infrastructure supporting this, I feel challenged. What should my colleagues be looking to do?

-It was stated that there had been a rate increase along with the SIS (Supports Intensity Scale) for residential settings, approximately a $4 per hour increase. The rates were tied into the SIS, despite the rate study that went along with it being grounded in the actual cost of delivering services. Even without the SIS, it still costs that much to deliver the service. This is important to consider when discussing the proposed Chapter III, Section 21 rule changes, pertaining to the rates.

-It was stated that it seems like this is setting everyone up to lose, that it’s a destructive plan rather than constructive plan.

-The proposed rules state that DHHS can tell an agency that they can terminate them if they can’t keep people safe, yet provider agencies can’t terminate unless there’s a safe place for them to go. It was stated that this is very risky for anyone with unsafe behaviors and could be harmful. It was stated that this let’s DHHS off the hook financially. It is troubling that this could turn into a system of supporting people with minimal service needs.

-It was stated that Community Support Providers usually have policies for people to remain at home if they are ill; however, home providers report that they don’t have the staffing to accommodate this. This is problematic.

-It was stated that it’s not uncommon for people on the waiting list to receive a service offer only to be unable to find an agency that can take them, because the agency can’t hire the staff to do so. Then, after six months of trying to find a provider, the individual has to reapply for the waiver. It was stated that it would be wrong to reduce the rates now; at the very least the rates should be left alone and have the next Legislature address them.

-Agencies are able to support the people with the lowest level of needs pretty easily. People with the highest level of needs are the ones receiving offers now. The new Behavior Regulations put an additional burden on agencies such as needing to train managers to write plans, oversee plans, and provide training; yet nothing was added in terms of a billable service to do any of that. Agencies hire staff to work with the most challenging people but can’t keep them because they can’t provide the level of training needed for the people with the highest needs. With the current rates, providers are competing with Walmart, Dunkin’ Donuts, and McDonalds, where people can work, make the same amount of money, and not have the worry of being bitten, hit, etc. Unless someone is very passionate and committed they leave for other employment.

-Community Connect wanted to educate family members on the proposed rule changes, and thus went through the Section 21 changes in detail and created an Action Alert, as well as a memo. The memo categorizes questions and comments within the key messages that DHHS presented to this group in August. This information may be beneficial for people as they develop written comments and testimony for the Public Hearing. One key concern is that what the Department provided in its one-page brief summary in August is different from what is within the 169 pages of the proposed rule changes. It doesn’t feel like a transparent process. *(*[*Click here for the Community Connect Action Alert and supporting materials*](http://www.maineparentcoalition.org/community-connect-action-alert.html)*).*

**Cullen:** I want to thank the members of Community Connect for going through the proposed rule changes and coming up with thoughtful comments and questions.

-It was stated that the same potential Section 21 clients are being funneled towards supported living, and sometimes DHHS is not disclosing potential safety risks prior to contract signing. This creates a certain level of distrust and is taking unnecessary risk.

-It was stated that in reading the rules there are certain aspects that are commendable in the sense that the Department is trying to move the ball in the right direction in certain ways; those efforts are appreciated. However, it was stated that there were issues regarding providers’ inability to remove people who are in dangerous situations. The rules state that the provider would have to keep providing services until they find replacement services; this puts a lot of pressure on providers from a liability perspective. There should be some provision that loops back to DHHS in a critical situation like that. It was stated that it is not believed that it’s the Department’s intent to shift responsibility solely to the provider, and give them no recourse; however, the Department should rethink this aspect of the proposal.

-It was stated that from a consumer advocacy standpoint it appeared the termination provision was a way of protecting individuals – to prevent situations when someone ends up in the emergency room and the provider won’t take them back. Having a safe place for someone to stay until an appropriate transition is found appears to make sense from this perspective.

-It was asked what an agency should do if a particular program is underfunded and the agency does not have the ability to provide that service. With this proposal, agencies cannot terminate services for that client.

-The proposals explicitly state: “No members will be affected through the proposal of this rule.” It was stated that this is not accurate and that the rules will affect individuals receiving services. It was recommended that the Department consider this next time it makes an announcement pertaining to its rules.

-It was stated that the Department’s inability to participate in discussions regarding the rules once they are put out for public comment creates distrust. A more collaborative way of everyone working together would be ideal because everyone is in this together.

**Ricker Hamilton, Deputy Commissioner of Programs, DHHS:** The Department’s inability to speak to rules out for public comment is a long-standing practice. I want to remind people regarding the work we did with the SIS (Supports Intensity Scale), people from around the country stated that they had never seen such inclusion and opportunities for feedback.

-It was asked if after the public hearing, and after the Department receives public comments, if there will be a time for collaboration and a dialogue with the Department.

**Ricker Hamilton:** Every single question will be answered and every comment will be addressed. This process for rule making happens across all state government.

**Cullen:** I just wanted to add two things. I have a son who turned 20 this summer. He’s a nice kid, really easy to work with, and people seem to enjoy being in his presence. However, like other parents have commented, his staff turns over constantly – he’s had 37 different staff. Each time a staff person leaves, often for jobs with McDonalds and Walmart, that’s another abandonment for my son, and another opportunity lost to help him develop and propel him forward to become a more independent, capable person. It’s sad each time this happens. It would be neat to figure out a way to professionalize the role of DSPs, because that’s where the rubber meets the road. The second thing I want to say is that this Coalition exists to be an information clearinghouse, a place where everyone can come together. It would be great if when the Department is designing aspects of the service system, people are able to participate fully in its design. I would encourage DHHS to get out in front of that with a working group, like the Coalition, so it feels like an inclusive process, with buy-in from inception through promulgation.

I want to thank Neal for his presentation and everyone around this table for a great discussion.

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

**Featured Topic: Service Timeline completed as part of a Leadership in Action Placement through the NH-ME LEND program and the University of Maine Center for Community Inclusion and Disability Studies.**

**Cullen:** Last year Alan Kurtz, from the University of Maine Center for Community Inclusion and Disability Studies, approached me regarding the LEND program, and whether the Coalition might benefit from a Leadership in Action placement. Since we aspire to have the Coalition’s website be an information clearinghouse, making it very easy for people to navigate and find important information, I thought this could be a great opportunity to expand on the information available on the Coalition’s website. When parents learn of their child’s diagnosis, many parents have no idea where to start, what steps they should take, where to get information, or how to navigate the service system. We thought that creating a simple timeline, covering the entire lifespan, with action steps and links to more information would be helpful to parents, family members, and individuals. Karen Sites worked with us to develop the timeline that we’re excited to present the initial draft version today. ([Click here for the Service Timeline](http://www.maineparentcoalition.org/service-timeline.html).)

**Cullen:** Please look at the timeline, let Vickey or me know how it can be improved, and tell us what might be missing.

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

**DHHS Update:**

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

**Cullen:** I wanted to say that it’s great to have you here, Ricker. We went so long without DHHS leadership around the table and having you attending is wonderful.

**Ricker Hamilton:** I don’t have an in-depth report, but I can tell you that the Department is closely monitoring costs per person going up. The Department is also looking at the way we deliver services, the demand on the waitlists, what we’re spending, and how can we be more effective. Section 21 and Section 29 are top priorities for all of us.

**Discussion:**

-It was asked how long it takes for someone to find an agency to provide services once an offer is received. It was also asked if the Department tracks what happens to people who are unable to find services.

**Ricker Hamilton:** I can get that information for you.

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

**Cathy Register, Resource Coordinator, Children’s Behavioral Health:** We have added approximately five new Section 28 providers in Region 1, including three specialized providers, some serving under-served areas. Part of Children’s Behavioral Health includes Judy Demerchant, a [Family Information Specialist](http://www.maine.gov/dhhs/ocfs/cbhs/fis.shtml). Judy receives a monthly list of people who are 16 years old to catch the kids approaching transition age who will need services. OCFS has also developed [A Guide to Transition Services in Maine](http://www.maine.gov/dhhs/ocfs/MSK.HDBK-update(6.23.16).pdf), which you may find helpful. [More information on transition can be found on our website](http://www.maine.gov/dhhs/ocfs/cbhs/transition-adulthood.shtml).

**Cullen:** For the December Coalition meeting we will have Teresa Barrows, Behavioral Health Director for OCFS, presenting, including a discussion about the [Blueprint for Effective Transition](http://www.maineparentcoalition.org/blueprint-for-effective-transition.html), which was created by the Coalition.

**Legislative Updates:**

**Cullen:** Congress passed a Continuing Resolution (CR), which funds the government through December 9th. That will fund programs at slightly lower levels than last year. When Congress returns after the November election they will likely work on an Omnibus package, which will include funding for HUD. I wanted to add that now is the perfect time to meet with candidates and your state Legislators, have them over to your house, and educate them on your son or daughter’s needs.

**Charlene Kinnelly:** I think there is a possibility that the Health and Human Services (HHS) Committee may be having a Committee meeting in November. There are a number of issues out there that the Committee would like an update on.

**Representative Peter Stuckey:** The Chairs of the Committee are trying to find a time and to agree on an agenda. When the Legislature adjourns, there’s typically a long time before the next session begins in January. Most of the time there are one or two Committee meetings in the fall leading up to the session in order to get updates on what’s been happening while the Legislature has been away. There will be a fairly specific agenda; I’m sure that Section 21 and 29 will be on it. The Committee doesn’t have the time to have a full-blown Public Hearing on these issues, but it’s important for representatives from this group to attend and share your perspective on what’s been happening, where we’re going, and where we need to go. The Committee was impressed with the Public Hearing and the Work Session held last spring; Committee members got a lot of really good information. When the meetings get announced, if you can be prepared to have a couple people there to tell us what’s happened since adjournment, particularly with Section 21, it would be helpful.

**Cullen:** With the election and the turnover on the Committee it’s particularly important that we continue to have a presence in Augusta. We have to bring new people up to speed about the needs of this population.

**Representative Peter Stuckey**: There’s been a lot invested in this issue on all sides. Committee members want to know what’s going on. Also, I wanted to let you know that the minutes from this meeting are being circulated within the Committee.

-It was asked if there was an update on the legislation that passed in the session before last which allows mid-level providers (dental hygienists) to see patients in lieu of a dentist (after a certain level of training and under the supervision of a dentist), which was discussed at last month’s meeting.

**Representative Peter Stuckey**: I’ll make sure we get an update on this.

**Disability Rights Maine (DRM) update**

**Staci Converse:** 57.2% of people with disabilities nationally did not vote in the 2012 election. We are holding voting trainings; there a couple this week, one at Momentum this Thursday, and one at Living Innovations in Saco on Friday. [More information is available on our website.](http://drme.org/)

**Announcements/handouts:**

**Cullen:** Cathy Dionne from Autism Society of Maine informed me that she has become aware of people who are dually diagnosed with ID/DD and mental illness being served by Section 17 receiving abrupt denials of service for their sons and daughters.

**Cathy Dionne:** In the last week and a half, three sets of parents have called about receiving Section 17 denial letters. Of concern, parents expressed being told that any individual getting Section 17 with a dual diagnosis including Autism were flagged. Now they’re getting denial letters. *(*[*Click here for the denial letter*](http://www.maineparentcoalition.org/uploads/2/6/1/1/26115022/section_17_letter_10.17.16_meeting.pdf)*).*

**Ricker Hamilton:** People won’t go without services. One-third of people were receiving Section 17 that didn’t need that level of service. There are other funding sources, including Section 65. Get in touch with the Department if anyone has questions or concerns.

**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:** Your three tasks between now and the next meeting are to **weigh in on the proposed rule changes, vote, and review and provide feedback on the timeline**. Thank you for attending, and thank you to our presenters.

Next meeting will be on **November 14,** and our featured speaker and topic are yet to be determined**.**

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).***