November 14, 2016

Minutes

Present: Nick Murray, Caron Murray, Lindsay Kidder, David Cowing, Mary Chris Semrow, Mary Lou Dyer, Katrina Ringrose, Meredith Inosencio, Emily Hough, Ray Nagel, Glenda Wilson, Arthur P. Clum, Todd Goodwin, Janet Rancourt, Nonny Soifer, Jennifer Putnam, Ricker Hamilton, Liz Weaver, Megan Meehan, Kathy Adams, Ed Doggett, Suellen Doggett, Margaret Cardoza, John Regan, Laurie Raymond, Julie Brennan, Erin Vogel, Kim Humphrey, Jamie Whitehouse, Sally Mileson, Richard Norton, Patrick Moore, Maura McDermott, Tyler Ingalls, Jerry Silbert, Cullen Ryan, and Vickey Rand. Via Zoom – Bangor (UCPofME): Andrew Cassidy and Karen Sites. Sanford (Waban): Morgan Jones. Biddeford (Community Partners, Inc.): Meg Dexter. Auburn (John F. Murphy Homes): Ann Bentley. Winthrop (Autism Society of Maine): Cathy Dionne. Gardiner (Uplift): Charlene Kinnelly. Orono (Center for Community Inclusion and Disability Studies): Bonnie Robinson, and Alan Kurtz. Brunswick (Independence Association): Laura Harvey, Jane Hart, Holly Randall, Mark Kemmerle, Carolyn Morse, Melissa Moore, Colleen Gilliam. Misc. sites: Jon McGovern 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: Ray Nagel, Executive Director, Independence Association.** [**independenceassociation.org**](http://independenceassociation.org/) **Topic: The DSP shortage and steps we could take to address the issue.**

**Cullen:** Today’s speaker isRay Nagel from Independence Association. At last month’s meeting we had a good conversation about DSPs (Direct Support Professionals), and challenges that we’re seeing in the system. We need the system to ensure there are DSPs who do the work necessary so that our sons and daughters receive the support necessary to be included as part of the community. This is where the rubber hits the road in terms of services. There appear to be some challenges within the system so we thought we’d talk more about that today.

**Ray Nagel**: I am the Executive Director for Independence Association, which is located in Brunswick. We employ approximately 240 people and provide services to approximately 400 people in the Brunswick area. We have a DSP crisis in this state. This is my second year with Independence Association where we will have an operational loss in our budget. In this particular fiscal year, we’re predicting a $270,000 loss, almost entirely attributable to group homes. Why is that? Our agency provides services to individuals along the entire continuum of care, including individuals with significant behavioral challenges. You don’t get additional funding for behavioral challenges – you get additional personnel, but when you have difficulty hiring that is not much help. Maine has always been at the forefront of providing services. Services in Maine are much more inclusive than other states, and the State expects inclusion. We should be proud of this.

**Begin Presentation**. [**Click here for the presentation**](http://www.maineparentcoalition.org/uploads/2/6/1/1/26115022/dsp_crisis_in_maine.pdf)**.**

**Discussion:**

**Mary Lou Dyer**: The 3X3 committee (which worked on the new rate system in 2007) was collaborative, sometimes contentious, but at the end of the day decisions were made by the Department. Though the committee didn’t necessarily agree with all of the decisions, they had the opportunity to air all of the issues they had. As such, no one was surprised by the result because it had been so thoroughly vetted.

**Ray**: The other significant thing about the decrease in the rates is the fact that the rates for the medical add-on were also reduced, and the behavioral add-on was totally eliminated.

-It was stated that DHHS funding, including any cuts, is not a partisan issue; cuts have happened during both Democratic and Republican administrations.

-It was stated that in order to cover unfilled positions, agencies are all using overtime, which is an additional expense.

**Ray**: This is a very good point. We’ve been tracking our overtime costs each year and they continually increase.

**Mary Lou Dyer**: I have a report that was completed by DHHS for the Joint Standing Committee on Health and Human Services (HHS), originally ordered by the Legislature. The report includes a review of the 200 costliest individuals in our system, at the time of the report. Although the data is old at this point, it is still relevant and valid in terms of seeing how Maine spends its money. It is apparent that the costliest are also the neediest.

-It was asked what the qualifications are for entry-level DSPs.

**Ray:** I can only speak for my agency, but we require a high school diploma, driver’s license, successful completion of a background check that passes the State’s criteria, and individuals must be 21 years of age or older.

-It was asked how the rates allow for the development of natural supports.

**Ray:** We try all the time, but the rates don’t support this. We do try natural supports, but a larger percentage of the people we support have significant behavioral issues.

-It was stated that everyone has some type of behavior issue. A self-advocate mentioned that Maine is not as well versed as other states on advocacy; Massachusetts and California both have better advocacy.

-It was stated that, as mentioned at the public hearings for the Section 21 and 29 proposed rule changes, there are people who could live semi-independently with electronic monitoring such as with the [Ibis](http://www.sensciosystems.com/ibis-overview.html). This would be a cost savings measure. -It was stated that DSP pay increases are critical. A parent stated that within a four-month time frame her daughter had four different DSPs – one DSP lasted only one day, another only one week. The DSP who lasted the longest, six weeks, left because she was pregnant and didn’t want to be in an environment with heightened risk of injury or harm, which is understandable. This is the reality facing parents and DSPs. It was stated that the Clinical Review Team (CRT) is another funding barrier for requests such as enhanced shared living, for which it will be more difficult for parents and guardians to advocate. This parent continued by stating that her daughter requires CPAP (Continuous Positive Airway Pressure) because she has breathing problems, common with 45% of people with Down syndrome. Her daughter’s CPAP mask broke, for the second time; she was sent the wrong mask and it was billed to her daughter’s MaineCare number. She spent the morning advocating through every existing avenue, including emailing the Governor, to remedy this situation. As of this meeting she had not made any positive progress on acquiring the correct, appropriate CPAP mask for her daughter. She called the Philippines, where the mask is sold, and discovered that she could pay $100+ out of pocket and have the mask shipped to her, but it would take seven to ten days for it to arrive. Meanwhile, her daughter will be waking up in the middle of the night, not getting a good night’s sleep, and not breathing for portions of the night – all of which affects her immune system, her health, her behavior, and her education. This was one morning in this parent’s life. Based on her experiences, she stated that she does not have faith that through the CRT, where parents must advocate for supports for their sons and daughters, the system will work, and that the Department will be responsible for needs of people such as her daughter.

-A parent stated that transportation is also a major issue due to the two-hour pick-up window. She stated that if her daughter has an appointment at 9:00am, she could be given a window between 8 and 10:00am, theoretically be picked up at 9:00am, arrive at the appointment at 10:00am, miss the appointment entirely, and her MaineCare could still be billed. It was stated that per ADA ([Americans with Disabilities Act](https://www.ada.gov/2010_regs.htm)), Title 3, people have the right to access their providers and services; the transportation system in Maine seems to be impeding this.

-It was stated that with enhanced shared living, if people want to change agencies they would have to re-apply for the service; because of this people are more apt to stay where they are which removes individual choice.

-A provider stated that hiring DSPs is extremely difficult; even offering $13 per hour someone could easily make $11 per hour at Walmart or McDonalds. This is extremely difficult work, for which it is tremendously difficult to hire. Completing a rate study as soon as possible would be extremely beneficial. It was stated that the qualifications and training requirements also have to be examined. Training qualifications are very difficult for people to meet. A provider stated that his agency cannot take on more people because they do not have the staff to serve them. He stated that everyone wants to eliminate the waitlists, however currently the system lacks the capacity to do so.

-It was stated that not only is this a problem on a consistent basis, it’s only going to get worse. The increase in need is greater than expected. It was added that until the system starts addressing co-morbid diagnoses much progress won’t be made on this.

**Katrina Ringrose, Disability Rights Maine (DRM)**: We are contacted about people not getting the services they need. Rates are one part of the discussion, and an important piece, but I don’t know if rates are the only solution looking at how we serve people with disabilities around the state. We also need to look at natural supports and qualifications.

-It was stated that group homes make up a good portion of Maine’s service system today, and the state lacks the capacity to turn that into something else overnight. As such, something needs to be done now. Often times people find the flaw in the provider; misinformation circulates that the crisis isn’t as bad as people think. It was stated that we need to look at our own Department of Labor (DOL), who in May 2016 identified the single greatest job vacancy in the state is for the type of position being discussed. Not only did the DOL find this to be the greatest vacancy, it is almost the most in demand.

**Mary Lou Dyer**: Theoretically I agree with Katrina. When I was thinking about coming to this meeting, the last meeting I’ll spend with you due to my retirement, even before I looked at the agenda, workforce issues were on my mind. A lot of agencies don’t provide Section 28 services. Why? There’s no staffing. It’s very difficult to pay people to provide in-home supports in families’ homes. I had an excellent discussion with OCFS (Office of Child and Family Services) staff regarding these issues and brainstorming solutions. These are not easy jobs. Absolutely, the rates are only part of the equation, but only when they’re adequate can you can delve into the other pieces of the puzzle.

-A parent stated that when her son isn’t adequately supported he becomes more aggressive. It’s difficult to find natural supports when someone like him would be in that lower state of functioning. When he is well-supported he flourishes and building natural supports is easier; people want to include him. It was asked what the plan is for the system to address this.

**Ray:** First I believe we must advocate for higher rates. Once these are in place it will stabilize the system. Then, we can collaboratively determine how we’re going to overhaul and rework the system for the future. However, the system has to be stabilized first, and the rates are paramount to this.

-It was stated that when staff leave it comes down to one reason: Going somewhere else to make more money. With the higher Section 28 rate there have been some successes with staff recruitment and retention. In was stated that Westbrook High School has a DSP class. Attaching some sort of credit towards schooling might be a win-win, as many positions require experience, which even with a degree is hard to acquire.

-It was stated that with a full spectrum of people who need care, it’s difficult to find adequate staffing for all needs.

-A parent stated that she has had to continuously fight for her daughter to learn how to read. Capitalizing on the education system is key. The laws in Maine state that people must be making progress on their IEP goals – progress can be .002%. In Massachusetts, people must be making the optimum progress possible toward their goals. Instead of having kids come out of high school with grade two reading levels, which will rapidly decline, we should be advocating for grade 4 or 5 at minimum, which is the reading level necessary for those skills to self-sustain. Kids should receive the optimum level of education so those who have the capacity to live semi-independently have better skills to do so.

-It was asked how the rates will work with the increase in the minimum wage. Effective January 1, 2017 Maine’s minimum wage will be $9 per hour, with incremental increases up to $12 by 2020.

**Ray:** In my organization DSPs are professional positions. When minimum wage increases they will expect at least the same level increase to offset their wage and minimum wage.

**Cullen:** This has been a great discussion. Ray, thank you for being here and for your informative presentation!

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

**Featured Topic: Follow-up on the 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 month we debuted the Service Timeline, which Karen Sites worked with us to develop. ([Click here for the Service Timeline](http://www.maineparentcoalition.org/service-timeline.html).) We asked everyone to review it and bring any feedback to this meeting so that we can continue to make improvements.

**Karen Sites**: This was my Leadership in Action project. The timeline includes information from prenatal care and birth throughout the entire lifespan, in one place where family members can easily access it.

-The group provided the following feedback: Include more information on prenatal care, testing, diagnosis, and Voc. Rehab.

**Cullen:** Please continue to look at the timeline, let Vickey or me know how it can be improved, and tell us what might be missing. I want to thank Karen for her work on this and Alan for continuing to set us up with wonderful LEND placements. This is a tool for everyone and we want to make it as great as we can.

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

**DHHS Updates:**

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

**Ricker Hamilton:** The Governor is also concerned with minimum wage. We’re also looking at the unfunded mandate from the DOL. In many ways we’re in the same boat; we’re looking at how we’re going deal with these factors the same as everyone else. I just want to remind people that the Governor’s last biennial budget included over $32 million to eliminate the waitlists. There may be challenges in doing so, but that was a pretty good commitment on his part. I don’t know who speaks for families who are not around this table. The waivers include priority levels which were setup during other administrations; maybe we can work on changing wording and looking at what they should be. You don’t have to go too far to look for rate studies. [Burns and Associates](http://www.burnshealthpolicy.com/) have done rate studies across the country.

Just as with the DOL mandate and increasing the minimum wage, there’s always the chance for unintended consequences. By expanding Medicaid, shortfalls were created which led to the 2011 rate cuts. There hasn’t been a supplemental budget requested for over three years. We have been able to put budget surpluses towards those most in need. The ability to do this is eliminated when you look at what other states are doing – what they’re funding and what services are getting cut. We should be advocating for those most in need. Sometimes people look for a quick fix. When the Governor’s budget allocated more than $32 million to eliminate the waitlists, about $2 million actually went into it, and through the Legislature the decision was made to put about $29 million towards other items. We need to speak with one voice and determine who is the most at risk. A large portion of funding goes towards group homes; we will have to work together and look at changes in the business model. The more we work together and not point fingers the better off we’ll be. I also want to ask parents to come testify at public hearings. Where were people at the hearings to eliminate the waitlists? The Department was the only one that kept saying the funding to eliminate the waitlists is important. We were met with deafening silence.

**Waitlist update**: There are approximately 1200 people on the Section 21 waitlist. The Department is constantly doing deep-dives into data. Staff are looking at projections for Sections 21 and 29 to project what the need is going to be. We’re trying to forecast, look at the cost, see where we can still provide services, and where we can work together to provide more services.

**Legislative Updates:**

**Mary Lou Dyer:** I am retiring at the end of this year. Proudly, I have been part of this group for eight years. I wanted to say how impressed I am with how this group has grown, how the parents have taken on causes and worked to have their voices heard. I’m impressed with Community Connect developing parent groups across the state. I was moved by the testimony I heard from parents last winter. I see the Coalition as the information hub. I’m excited about the work you’re doing. For the legislative update, figures won’t be final until tonight but it appears that the Senate will have a 1-seat Republican majority, and the House will have a 4 to 6-seat Democratic majority. It doesn’t get much tighter than that. There will have to be a collaborative working relationship between the two major chambers and the Chief Executive. It will be an interesting two years. It has been a supreme privilege and pleasure to work with you all. (Large round of applause).

**Cullen:** Congress passed a Continuing Resolution (CR), which funds the government through December 9th. This funds programs at slightly lower levels than last year. Congress returns today, and they will likely work on an Omnibus package, in which Congress would consider funding for HUD. Where this will land is unclear at this point.

**SMACT (Southern Maine Advisory Council on Transition):** The next SMACT meeting is on Friday, 12/2 at the Martin’s Healthcare Campus (Jewell Room in Building 5, 331 Veranda Street, Portland). The topic will be Supported Decision Making / Alternatives to Guardianship, presented by Lydia Paquette, Staff Attorney from Disability Rights Maine.

**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.

Next meeting will be on **December 12,** **2016**. **Featured Speaker: Teresa Barrows, Behavioral Health Director, DHHS-OCFS. Topic: An update on OCFS and a follow-up on the Blueprint for Effective Transition.**

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).***