April 11, 2016

Minutes

Present: Ed and Suellen Doggett, Valerie Smith, J. Richardson Collins, Liz Weaver, Lily Lin, Dee Karnofsky, Perry Blass, Jeff McFarren, Betsy Mahoney, Kim Humphrey, John Bald, David Lawrence, John Regan, Christine Campbell, Megan Meehan, Dina Martinez, Bob Duranleau, Glenda Wilson, Gil Moreno, Jennifer Putnam, Jerry Silbert, Staci Converse, Patrick Moore, David Cowing, Julie Brennan, Todd Goodwin, Patricia Miles, Julie Snook, Tyler Ingalls, Cullen Ryan, Vickey Rand. Via VSee – Bangor (UCPofME): Andrew Cassidy. Westbrook (Woodford Family Services): Stacy Lamontagne. Sanford (Waban): Morgan Jones. Biddeford (CPI): Meg Dexter. Gardiner (Uplift): Darla Chafin and Charlene Kinnelly. Farmington (Leap): Darryl Wood and Joyce Daggett.

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: Valerie Smith, Ph.D., Executive Director, Maine Developmental Services Oversight and Advisory Board (MDSOAB).** [**www.mainedsoab.org**](http://www.mainedsoab.org/) **Topic: Public Feedback Forum 2015: What We Learned, and What's Next.**

**Cullen:** Valerie has been working hard, going around the state holding community forums where people had the opportunity to weigh in on how the system is working, what could be improved, and provide other feedback. She does a very nice job compiling this information and putting it into a report at the end of the year. Today you’re getting the first look at this outside of the MDSOAB. Thank you for your work on this and for presenting today!

**Valerie Smith:** Thank you for inviting me! We hold the forums annually and in collaboration with other agencies, including the [Center for Community Inclusion and Disability Studies](https://ccids.umaine.edu/), [the Maine Developmental Disabilities Council](http://www.maineddc.org/), [Speaking Up For Us](http://sufumaine.org/) (SUFU), [the Volunteer Correspondent Program](http://vcpmaine.org/), and [Maine Parent Federation](http://www.startingpointsforme.org/).

The Community Consent Decree required the State to provide services for Class Members who had been released from Pineland. As part of the Consent Decree, a Consumer Advisory Board followed each individual to ensure the State was doing what it was charged with doing. In 2007, the Department of Health and Human Services (DHHS) petitioned to be released from federal court supervision, thus ending the Consent Decree. At this point in time the Court Master put the MDSOAB in place. The MDSOAB is responsible for oversight of the ID/DD system as a whole, with the goal of improving the system of supports. Each year we hold forums to solicit feedback to accomplish this. The forums are held in different parts of the state each year; this year we went to Norway, Biddeford, Brunswick, and Aroostook county. We also developed three surveys aimed at different audiences – individuals, family/guardians, and providers. We take all of the comments and look at the overarching themes, which is what I will be presenting today. I have broken the presentation down into the main themes that emerged from the forums, and hope to have an interactive dialogue soliciting further feedback from this group.

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

**Communication Discussion:**

The group offered the following feedback: Make websites adaptable; there are a lot of people who are deaf or hard of hearing, and some of those individuals have family members who are as well, so having information/materials on websites signed in American Sign Language (ASL) would be beneficial – USM interpreter students might be able to assist with this; if ASL is used, it is preferable not to include captions as well, as having both is too distracting; as a standard procedure, communication that is sent to the individual should be send to the guardian as well; letters from the Department are demanding and the tone can be very punitive; in addition to physically mailing letters, it would be helpful to have them sent via email as well; communication is very frustrating, to the degree that sometimes individuals want to give up on services altogether; DHHS should deliver a message that isn’t overly complicated, with clear next steps if applicable; it’s incredibly difficult to contact the Department, even when matters require prompt response; the centralized phone system for DHHS has become almost impossible to navigate; even going to a DHHS office isn’t an option as staff aren’t present to see people.

**Crisis Services Discussion:**

The group offered the following feedback: When you call crisis services it doesn’t go to a specific department (Developmental Services, for example) which can be confusing; often times you have to wait for a person to call back, and that additional time can result in the crisis escalating; people have been told that crisis services can’t make it there on the same day as the call, and instead people should call 911; DHHS needs to ensure that the people staffing the crisis system are trained to address mental health in addition to ID/DD, and that they can make proper judgment calls to get people to the right services and the help they need; crisis staff are terrific once they’re involved, but getting to that point is very difficult; there is a gap in the availability of crisis services (weekends, etc.); non-state run crisis services (which contract with DHHS) tends to shy away from people with complex medical and behavioral needs.

**Guardianship Discussion:**

The group offered the following feedback: In Maine, the case worker can be the guardian as well as the Rep Payee – this is a conflict of interest and should be addressed.

**Person Centered Planning (PCP) Discussion:**

The group offered the following feedback: The PCP process used to gather people who know the person very well, start with a long-range plan, and then decide how to get there – it was a real *process* that mirrors the process people without disabilities go through in their everyday lives; there is a huge cliff after high school and there is no transition process; there needs to be accountability for ensuring goals are achieved; the individual should truly have control over the PCP process.

**Employment/Voc Rehab Discussion:**

The group offered the following feedback: Voc Rehab (Vocational Rehabilitation) is charged with obtaining, maintaining, and advancing employment for an individual – this isn’t necessarily happening in practice and needs to be remedied; staff training should be much more accessible; the system needs to get away from focusing on simply checking a box.

**Valerie:** This presentation is a small portion of what is included in the full report. If anyone wants more information or information on topics we didn’t cover in this presentation you can find it in the full report.  *(*[*Click here for the full report.*](http://www.maineparentcoalition.org/april-2016-presentation.html)*)*

**Cullen:** Thank you for your work on this Valerie; well done!

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

**DHHS Update:**

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

**Cullen:** The Department is unable to have anyone from the Office of Aging and Disability Services (OADS) in attendance today. Karen Mason has stated that she would be in touch regarding the Department’s future attendance. Everyone here is in agreement that it is important to have OADS at the table. I am hopeful that they will be able to attend next month.

**Legislative Updates:**

**Charlene Kinnelly:** This entire Legislative session has been very unusual. As certainly most of you know, thanks to the Coalition, Community Connect, and the very obscure process outlined in statute, the Legislature was successfully petitioned by 264 people to review the proposed Section 21 rule changes. Over 1500 people signed a support petition, expressing their concerns in addition to the original petitioners. As a result of this, the Health and Human Services (HHS) Committee held a public hearing where many of you were present and testified. The HHS Committee reported out a bill requiring that the Section 21 rules become Major Substantive. Once the legislature finishes its process it would go to the Governor for signature. At this point the Governor would sign it, veto it, or the bill would become law without his signature. If the bill is vetoed, it would require two-thirds majority vote in both the House and Senate to override the veto.

The Legislature was also petitioned regarding the Section 17 rule changes. Section 17 is another section of the MaineCare benefits manual that provides services for case management and daily living skill support for individuals with serious and persistent mental illness. The Department changed the rules limiting the eligible diagnoses for Section 17 services to Schizophrenia and Schizoaffective Disorder. Thousands of letter were sent to recipients of Section 17 services stating that they may lose their services as of 4/8/16. The legislative petition resulted in a public hearing in front of the HHS Committee on Friday, 4/1 that lasted until 10pm. The Committee worked very hard, and worked with the Department as well, to come up with a compromise. It’s important to note one major difference between the Section 21 rule changes and the Section 17 rule changes – the Section 17 rules had become final whereas the Section 21 rules were only proposed. A compromise was achieved which extended the period of time for people who will no longer be eligible for Section 17 to transition to other services within the MaineCare program – up to 6/30/2017 if a person is unable to find alternative supports. That resulted in a unanimous Committee vote of ought to pass as amended. With this unanimous Committee vote the likelihood of that bill surviving is much greater.

[Burns and Associates](http://www.burnshealthpolicy.com/), the group that did the rate setting study for Section 21, has been consulting with the Department and is in the process of doing a similar rate report for other MaineCare Section, including Sections 13, 17, 28, and 65. These sections provide services such as case management, medication management, and preschool and school-age special purpose programs for kids with significant disabilities. The rate study proposes substantial rate cuts to these services; a significant number of individuals would be affected by the rate changes. There had been a resolve asking that the HHS Committee decide whether or not they should report out a bill putting a moratorium on the rate changes until after January 1, 2017, when the Legislature will be back in session. This would effectively ask the Department not to rush this through without legislative involvement. There was an HHS Committee meeting where Committee members had the opportunity to speak with Department staff to gather information to determine whether or not to hold a public hearing. This did not go well. The Department was asked several times whether they would be willing to move forward with the rate study but wait until after January 1, 2017 before implementing the rate changes. Long story short, the Department’s answer was no. This resulted in a split vote along party lines; a motion was made to draft a bill delaying the implementation of the rate changes, and the vote was seven supporting and six opposing that motion. That bill will likely die.

LD 475, Representative Stuckey’s bill to increase the Section 29 cap to 40 hours per week, is still alive but it’s on shaky ground. The Legislature is supposed to adjourn on April 20th; however, there is no budget, there are many bills that are hung up, and overall it’s very chaotic. Some members of the Appropriations Committee were working on coming up with a bill addressing the funding needed for LD 475; though, when the Senate and the House started disagreeing the fate of that became uncertain. However, I haven’t given up hope yet!

**Cullen:** That was a great report Charlene, thank you very much.  Let’s hope LD 475 gets through and the Department gets back to working more inclusively with us in system design.  I want to thank you as well as Mary Lou Dyer; you both have been working tirelessly to convince Legislators that this truly is a bipartisan issue.  Over the past few months I’ve sent a lot of action alerts to members of the Coalition.  I want to thank you all for your responsiveness on numerous different issues throughout this legislative session.  Members of this Coalition have raised their voices by signing petitions, contacting Legislators, and giving testimony.  This has made an incredible difference – your voices have been heard and we are all better for it.  Thank you!

I also wanted add that the changes to Section 17 effect a certain portion of people with ID/DD.  In an action alert I had asked this Coalition to weigh in.  The net result was that 300 people were present for the hearing, and 117 people testified. The Department is swiftly trying to implement changes that have major implications – we’ve asked them to slow down. The HHS Committee has done amazing work this session, allowing opportunities for our voices to be heard and for opportunities to inform the Legislature, providing a clear picture of the real effect the various proposed changes would have on our loved ones.  Many of us in this room spent a great deal of time raising our voices; we’ve been a force to be reckoned with.  We have more to do, but this has been a great showing of advocacy.  Well done.

Additionally, I wanted this group to be aware that Todd Goodwin recently drafted a letter to the Department regarding having an inclusive dialogue around any planning alternative to the SIS (Supports Intensity Scale), which this group has advocated for. ([*Click here for the letter*](http://www.maineparentcoalition.org/april-2016-presentation.html).)

**Todd Goodwin:** I don’t believe any of us are under any illusion that what may come next will be more favorable than what we were confronted with last time. We’ve gathered a broad coalition, representing various interested groups throughout the state, and composed a formal request to the Department to engage, from start to finish, in any planning alternative to the SIS. The letter went out today. I’m quite hopeful we’ll get a positive response so we can assemble a small group to work truly transparently and truly collaboratively with the Department in what they seek to put forth as an alternative to the SIS.

**Developmental Services Stakeholders Continuum of Care Updates:**

**Cullen:** The group is currently meeting every other month (even numbered months). We met last week and received information from OADS regarding the waitlist numbers. **Waitlist numbers:** Currently, there is not a waitlist for Section 29, but the time it takes between application and receiving services is between two and three months. Currently there are 1253 people on the Section 21 waiting list: Priority 1 = 0; Priority 2 = 415; Priority 3 = 838. The Department still has not offered clarity on how people are being selected for Priority 2 offers.

**Disability Rights Maine (DRM)** [**drme.org**](http://drme.org/)

**Staci Converse:** The new behavior regulations should be out within the next couple of weeks; we are keeping our eyes out for them.

**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.

**Handouts/Announcements:**

* At the federal level, there have been amendments to the ABLE Act; now you no longer have to sign up for an account in your own state, so people in Maine do not have to wait until the state moves forward with legislation.
* There is a Community Support Expo on 5/24 from 5-7pm at Husson University in Westbrook.
* For the May 9th meeting, a different application, Zoom, will be used for video conferencing with the remote sites. The process should be much easier, and the quality of the call should be markedly improved.

**Cullen:** At our next meeting on **May 9, 2016,** our featured speaker will be **TBD. Topic: TBD.**

Unless changed, Coalition meetings are on the 2nd Monday of the month from 12-2pm.

***Burton Fisher Community Meeting Room, 1st Floor of One City Center in Portland (off of the food court).***