January 11, 2016

Minutes

Present: Cathy Register, J. Richardson (Jay) Collins, Mike Charley, Beth MyLroie, Sarah Kaleko, Perry Blass, Jennifer Putnam, Julie Brennan, Diane Boas, Mary Chris Semrow, Romy Spitz, Staci Converse, Debbie Dionne, Kim Humphrey, David Thompson, David Cowing, Peter Stuckey, Maura McDermott, Mark Lawrence, Lauress Lawrence, David Lawrence, Julie Snook, Arthur P. Clum, Patrick Moore, Jerry Silbert, Wendi O’Donovan, Luc Nya, Lorie Dorrance, John Regan, Kathy Adams, Bob Duranleau, Laurie Raymond, Amanda Eisenhart, Cullen Ryan, Vickey Rand. Via VSee – Auburn (John F. Murphy Homes): Ann Bentley and Darla Chafin. Bangor (UCPofME): Andrew Cassidy, Peter Alexander, Charles Shaffer, Tracy Beauregard, Marc Beauregard, and Catherine Robertson. Westbrook (Woodford Family Services): Stacy Lamontagne. Biddeford (CPI): Meg Dexter. Sanford (Waban): Morgan Jones.

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 speakers: Diane Boas, Parent and Healthcare and Disability Consultant. Topic: Section 29 Toolkit**

**Cullen:**  Last month we had a group of people present on Community Connect, which is activating parents’ voices in a new and exciting way. This proved itself to be very successful, as last week 150 people showed up, and 41 people testified over five hours, all expressing concerns/opposing the proposed rule changes for Section 21. I want to acknowledge the excellent work of Community Connect in terms of mobilizing people at a particularly important time for them to be heard. We have much more work to do, but we will discuss that later on in the agenda. It is notable that we don’t have OADS represented today. Our speaker today is continuing the idea of parents grabbing the bull by the horns, telling the system how it should work and in turn helping us become better parents by improving our understanding of the system and how it works for us. Diane Boas was commissioned through the Maine Developmental Disabilities Council (DDC) to create a Section 29 toolkit, which she will walk through today. Her comprehensive toolkit will be linked in the minutes and will be published on the Coalition website once it is finalized. Thank you Diane, you have put in a tremendous amount of work! (*Round of applause.*)

**Diane Boas:** We work so hard advocating for our kids. I was fortunate to have a lot of discussions with Rachel Dyer from the DDC when putting the toolkit together. They have funded my work and hopefully they will fund lots of other work! The timing of this is related to the fact that so many families were taken off of the waitlist for Section 29 as a lot of offers were made. However, a lot of people are not accepting these offers. It’s very likely that many families may not fully understand this waiver, or they may be having trouble making decisions while their children are still in high school. This toolkit is designed to help families for whom the offer is being made and who currently have the Section 29 waiver. It is written to be user friendly; it also has tools so our adult children can use it as well. The formatting isn’t finalized; this is still a work in progress. The primary purpose of the toolkit is to describe services, give families tools for choosing services, and provide tools for evaluating those services. I received a lot of input from families around the table as well; I’m very grateful for their assistance. Fortunately Section 29 has now become more comprehensive and covers a broader array of services. The changes, which were suggested by the Coalition, make it a little bit easier – but whether to accept the service is still difficult a choice. A lot of families are sacrificing some in-home support services to accept Section 29. It’s not perfect but overall it is an improvement. Within the toolkit I tried to ask some of the hard questions to make the system more transparent for families.

***Begin Presentation.***[***Click here for the Section 29 Toolkit.***](http://www.maineparentcoalition.org/january-2016-presentation.html)

**Diane:** Regarding employment, too many families are told their child is “too disabled to work.” This is heartbreaking. The message in Maine is “employment first.” Then, a VR ([Voc Rehab](http://www.maine.gov/rehab/dvr/)) counselor determines that your child can’t work. This is confusing for parents and it isn’t true; there are ways to contest that.

**Jay Collins:** There are a few layers to this. There is the Employment First legislation, and what the Director of VR says.Whether that’s trickling down into practice remains inconsistent. On the other side, there are layers to qualifying for VR services. Some people are presumed eligible. However, even when someone is presumed eligible it has to be determined that he or she will benefit from VR. Through this, a lot of people with disabilities almost defacto end up labeled as too disabled to benefit from services. There is a big push in the state of Maine for this to become a defunct status. Though, it will likely take a lot of time for this way of thinking and operating to trickle down from the top. Everyone can work, but when you interface with VR you have to make it past the ability to benefit from services marker. Also keep in mind that you can always challenge a determination. VR will have to show what they did to make a determination, and how what they did demonstrated the final decision.

**Diane:** I can already see this is a section I can add to! Another thing, which I think has changed, we were told to start with day hab and then move on to employment. Employment should be the end goal so we should be getting people into work right away. Work is a great opportunity for creating options for unpaid supports as well. The section of the toolkit on evaluations is very important. This is where Maine is pioneering. We don’t tend to ask enough questions, such as: Is it really effective? How can we raise the bar? What else can my child get out of this? How can we be sure it’s working? I really want this toolkit to help people think differently and to be sure they are getting the most out of their services. This is a living document. As we create other tools, or as other states do, they will become part of this.

**Discussion:**

-A parent stated that parents needs to do a certain level of training with providers, with the realization that the person working with your child is getting $10-$12 per hour with a limited amount of training. This can be done in a very professional way that builds the relationship and educates at the same time.

**Diane:** That’s a great point. In my experience there are some fabulous day programs out there. I’ve found that providers want to do better.

-A parent stated that when it comes to evaluating services and experiences there is a need to go down another layer and ask even more basic questions, especially for employment, such as: Do they know your name? Do they know what your needs are? Do you know what to do if there is a fire in the building? It was stated that people need to be held accountable in these regards as well.

**Diane:** You raise some good points. We don’t want to overlook some very basic stuff. Each of our children are so different and have different goals for what they’re going to receive in the work place. This is a great recommendation.

-A parent commented that for parents they will always be their children, nothing there changes. However, the people providing services will change; they will change dramatically and sometimes in a very short period of time. It was stated that it’s very important to be involved in the services and the agencies providing the services. A parent stated that he knows his son’s manager, supervisor, and people who work with him, as well as his day hab program. He stated that no matter what type of services are received, parents are still the key people to make it all work.

**Diane:** I think it’s true. It’s the hardest job and it’s frustrating. For those of us who can do what you outline – it’s great. There are some parents who can’t. Also, we want our adult children to be true partners with us and, where they can, to be directing themselves. If I gave my son a list of questions he could ask people those questions and in time would get comfortable with them. I think ultimately we want to be in partnership and promoting their self-determination. We also have to be realistic. If providers have these tools maybe they can reach out more to those consumers and/or families who may not feel comfortable in an advocacy role.

-A parent stated that the Section 29 Toolkit would be great to use during annual or twice a year meetings with providers, making them aware that parents will be asking these questions. A parent stated that it is a challenge for her daughter to ask questions; the tool could empower her, especially if she knows in advance.

**Diane:** This is a good point. Both programs that provide day services for my son would include this in a packet they hand out in the beginning. This can help set the bar for providers.

-It was asked when the toolkit will be made available?

**Diane:** The toolkit is not done and it is a fluid document. If you have any suggestions or questions you think other parents would benefit from knowing, they can be included. At the very end of the toolkit there is a survey to gather feedback and suggestions as well.

-A parent stated that just like their sons and daughters have vast range of abilities and situations, so do the families. The people in this room could use a tool like this – it is a wonderful tool. It seems like the system we have is based on quality case management services; case managers need to be trained on families. It might be advantageous to put an emphasis on how people use their case managers, and to ask questions like: How are case managers guiding your child’s needs?

**Diane:** This is true. There is tremendous turnover in case management because of the demands, all the paperwork, etc. It’s not that I want to take the responsibility away from them. Usually I don’t want to wait for my Case Manager to figure it out – I want to know what to do.

-Someone from the group stated that parents being actively involved is important. However, parents aren’t often able to be as actively involved as they’d like to be. The system has a tendency to put a lot on parents. He also stated that eliminating the State Office of Advocacy was erroneous; the group ought to revisit establishing a State Office of Advocacy, as this group was paramount in advocating for people. It was a consistent, appropriate, and powerful tool. He stated that he was not satisfied that it transitioned appropriately to Disability Rights Maine.

**Staci Converse, Disability Rights Maine (DRM):** If you have any questions, comments or concerns, please do not hesitate to reach out to me directly. I would be happy to discuss this with you.

**Diane:** We need as much help as possible in regards to advocating. This toolkit isn’t the end-all and be-all, but it is a good step towards helping us be more informed. The more we understand services, the more we can maximize them and be better off for it.

-A parent stated that there is a large gap in terms of recognition of comorbid medical diagnoses. If Section 29 addressed this it could be an effective tool; because it doesn’t people become inappropriate for services. Parents are hard-pressed to make a living with the limited number of hours covered by Section 29. If the system doesn’t address the medical aspect of people’s needs, no matter the good intentions, they won’t be served well. The Department is very good at many things, but a huge gap remains in regards to the medical aspect; it’s a major, problematic gap.

**Diane:** I think I will add a section on the medical aspect, as it is important. I don’t want to make it sound like this is easy. It’s not. I think we all just have to keep plugging away to make it work.

-A provider stated that he would give the toolkit out. There are some great case managers and DSPs at his agency, but they want to know these things as well. Parents sometimes have unrealistic expectations of programs, and are surprised when they don’t resemble classrooms. There are some folks who really don’t have a clue, and they could benefit from this tool. Parent involvement is key; it’s a relationship. It’s a moving organism with a lot of pieces.

-It was asked how this information will be disseminated to families who may not be connected with the various and plentiful groups with far reaches around the state, such as the Coalition.

**Diane:** It will be on theon [Maine Developmental Disabilities Council](http://www.maineddc.org/) website, [the Coalition](http://www.maineparentcoalition.org/) website, and possibly on the [DRM](http://drme.org/) (Disability Rights Maine) and [DHHS-OADS](http://www.maine.gov/dhhs/oads/) websites.

-A parent stated that the IBIS Remote Monitoring System, which was presented by [Senscio Systems](http://www.sensciosystems.com/) at the October meeting, could be used in a cost-effective manner to determine if people are meeting goals, taking medications, etc. There was also discussion regarding the need to drive the effort to better transportation. Medicaid dollars are being spent to have someone stuck in a car for two hours; the transportation system ought to do better for our kids.

**Mike Charley, Senscio Systems:** Regarding the IBIS system, we are just starting two programs in South Dakota. One is with the South Dakota Parent Connection, a group very similar to the Coalition with 4000+ members. We’re also starting a project with a group of community service providers there. They have gone to their DHHS office and received permission for some of the HCBS (Home and Community Based Services) dollars to be spent on the IBIS system. There are about 30 different activities of daily living that can come up as tasks now, for which we’re currently working on protocols. There is one “super user,” a nine (9) year old girl with Cerebral palsy, who is unable to use the system herself but loves it and tells her mom when a task is coming due. We have also included a document repository specifically for parents, so they have full control over the documents and permissions for every provider. The IBIS system is proving to hold great value, helping both the individuals and families manage. I would love to talk to anyone with interest in IBIS.

**Cullen:** Thank you very much Diane, both for your presentation and your work putting this incredible tool together! Well done!

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

**DHHS Update:**

**OADS, DHHS -** [**www.maine.gov/dhhs/oads**](http://www.maine.gov/dhhs/oads)**: A representative from DHHS could not attend but Karen Mason emailed waitlist numbers in advance of the meeting. Waitlist numbers as of 12/31/15:** There are 1259 people on the Section 21 waiting list: Priority 1 = 0; Priority 2 = 465; Priority 3 = 794. The number of members waiting for a Section 21 funded offer, and are receiving or are offered Section 29 services = 944. The Department continues to offer all identified as Priority 1.

**Email update from Karen Mason:** The waiver manager continues to make offers to those individuals who meet the definition of Priority 1 and in addition has begun making offers to those in the Priority 2 category from the funding that was authorized by the Legislature. In addition, those who having been requesting Section 29 services post-June 30th have now begun receiving offers. As a reminder there was a bit of a delay as OADS was working through the high number of individuals that were offered this service through the end of June and had yet to respond. Next month I can provide more detail in both areas.

In terms of a couple of key positions here at OADS: We will be making a decision soon on a new hire for the Developmental Services Program Manager position. We are also currently in the process of interviewing for the Adult Protective Services Program Manager position (this is why I am unable to participate today).

Please let me know if folks have questions that I may answer prior to the dissemination of notes generated today.

**Discussion:**

**Cullen:** Does anyone have questions for the Department, which will be answered in the minutes?

-The group came up with the following comments/questions:

* The group stated that they are looking forward to hearing about how OADS makes the determination for extending offers to people on Priority 2, which was scheduled to be discussed today.
* An observation was made that there is a pattern of the Department not being at the table. This is one of many venues they’re noticeably absent.
* “This is being discussed in many venues” is a common response from the Department when questions are raised. However, the questions seem to remain unanswered.

-A parent inquired about the changes to Section 29.

**Cullen:** Section 29 previously only covered day hab services related to employment. Through the White Paper, this Coalition called for making Section 29 very similar to Section 21 in terms of services available. This has come to fruition, the only major difference being that Section 29 is capped at around 21 hours per week. For more information you can [visit the White Paper page on the Coalition’s website](http://www.maineparentcoalition.org/dd-continuum-of-care.html). Additionally, previously someone couldn’t receive Section 29 while he or she was still in school; this has also changed. The Coalition has engaged in an ongoing discussion on the need to raise the Section 29 cap. As Karen reported, there are 1259 people waiting for Section 21, 75% of whom are getting a limited number of services through Section 29, up to this cap. We, and others, have suggested raising the Section 29 cap up to 40 or 50 hours per week so parents would have a feasible way to remain employed. Raising the cap, for some, may eliminate the need for the more intensive services (exceeding 40 to 50 hours per week) offered through Section 21. Representative Stuckey introduced a bill in the last legislative session regarding this.

**Representative Peter Stuckey:** The bill from the last session was carried over (*LD 475, “Resolve, To Increase MaineCare Services for Certain Recipients To Allow Them To Remain at Home,” introduced by Representative Stuckey.*) and it seeks to expand the Section 29 cap, essentially expanding the number of hours per week covered by the service. This would bring Section 29 closer to resembling Section 21, and would likely serve a large percentage of people adequately, possibly to the point where there isn’t a need for them to utilize Section 21. This spurred discussion, with questions like “Why don’t we just have one waiver?” The Work Session for the bill is scheduled for Thursday, January 21st at 3:00pm in front of the Health and Human Services Committee. The Committee Chairs have asked the Department to broaden the scope of the session to include an update on the implementation of the changes for Section 21, which you all were so eloquent in describing at last week’s public hearing. Some key people should have been actively listening at that hearing. Hopefully the conversation that started last week will continue in our committee room at the work session. We are still struggling with whether or not the Department will be present. We are moving forward with the work session on 1/21, but the bill could be amended in any number of ways.

**Cullen:** The effective advocacy around expanding the Section 29 cap has triggered discussion of having only one waiver. One of our waivers has a waitlist of 1259 people, and the other waiver doesn’t reach all the way. If we can get Section 29 to expand the cap so it stretches up higher, so parents can work full-time jobs, it could work for upwards of 85% of people. This is key. However, it is premature to discuss only having one waiver until the Section 21 waitlist is eliminated.

**Representative Peter Stuckey:** The primary function of the carried over bill is to get the extra hours included under Section 29 so it works better. We are expanding the work session based on what I heard last week. What was intended to be a tool (the SIS) to inform the PCP (Person Centered Plan) has in fact become the maximum of the PCP process, with services reduced from their current levels. That is so far removed from the intention of those of us who took part in the legislative process and worked to understand and support what you were saying would work well. I hope we’re able to shine a light on this next week.

**Cullen:** Thank you for this, and thank you for being at the hearing last week.

-It was asked whether comments will be sent regarding the Section 21 proposed rule changes on behalf of the Coalition.

**Cullen:** That is up to the group. Comments are due by midnight on Friday, January 15th. This is your chance to weigh in. Does the Coalition want to weight in as whole on this? (*Many from the group nodded in agreement*). When I testified I did so as a parent. My testimony included: Pointing out that DHHS has been missing at the table when there have been a lot of opportunities for them to hear from us; stating that the SIS is being weighted too heavily in the proposed rule and that the SIS should be secondary to the PCP process, not the other way around; and that using the SIS for rate setting essentially creates a several-sizes-fits-all model, creating a narrow pathway leading to five boxes, into which people must fit. We have been working diligently to move away from a one-size-fits-all system and towards a system that meets each person where they are at, providing services appropriate for each person – no more, no less. My testimony doesn’t reflect the issues others have noted about the Qualified Extra Support Service (QESS), which I would suggest including. The Department has built in and relies heavily on QESS to provide support above and beyond the assigned SIS levels. However, there appear to be flaws in the way the rules are written pertaining to this service. The qualifications needed by the direct support professional (DSP) providing this service are very extensive, and likely very difficult to attain. The DSP must have a minimum of three (3) years’ experience working as a DSP in either Home, Community, or Work Supports, on top of an enormous list of other qualifications. There is a lot of turnover, especially among DSPs, at agencies; providers around this table often report that it is increasingly difficult to retain staff. The QESS process is therefore flawed, as provider turnover happens faster than the three (3) year minimum requirement for providing QESS.

-The group discussed the Section 21 proposed rule changes, the lack of Department transparency, and the fact that from its inception the SIS was always seen as complimenting the planning process not coming before it. Many parents expressed their concerns with the SIS levels as they were not representative of their children’s needs. It was discussed whether or not the proposed rule changes where in compliance with the CMS ([Centers for Medicare and Medicaid Services](https://www.cms.gov/)) rule.

**Staci Converse:** Cullen’s testimony was fantastic and I think it would be very representative of this group. There is one piece that I would like to add regarding the QESS. There is a huge problem with how the process for attaining those services is defined. According to the proposed rule changes, “the service will be available to a member upon completion of a review process and an approval by the Extraordinary Review Committee (ERC). The ERC will review the necessity for additional hours of qualified staffing to meet a documented extraordinary support need.” The way it is written, there is no standard for how a person qualifies for QESS. Without transparent written standards, contesting the Department’s determination, as is a consumer’s right according to the Department’s appeals process, is considerably more difficult. This is a real problem, and an important part of this whole scheme.

-It was stated that there is a small group of providers circulating a petition to have this matter be considered major and substantive and go before the Legislature. It was stated that people can petition the Legislative Council to have this heard.

**Representative Peter Stuckey:** I don’t want to short circuit this, but one of the positives of the carry over bill is that it already exists. I encourage you to come next week and talk about this, as it’s possible the bill can be amended. I have already spoken about doing exactly that. However, keep doing what you’re doing. The Legislative Council is a good back-up plan. You can get a bill into the Council, but to get it through to the Legislature you need a majority of the Council to approve it, and with the ten members of the Council split evenly among party lines it could stall there.

-The group indicated that Cullen’s testimony, with the inclusion of Staci’s comment regarding the QESS, represents the Coalition’s stance.

**Cullen:** I am happy to write testimony on behalf of the Coalition. Would a volunteer group of three to five people be willing to read it before I send it out on Friday? *(Dave Cowing, Diane Boas, Jerry Silbert, Arthur Clum, and Kim Humphrey all volunteered to read the draft testimony.)*

* A motion was made, and seconded, for Cullen to submit testimony on behalf the Maine Coalition for Housing and Quality Services as public comment for the Section 21 proposed rule changes. All were in favor.

**Cullen:** Check out our completely revitalized 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 new 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.

**Other updates/handouts:**

* Friday’s SMACT ([Southern Maine Advisory Council on Transition](http://blogs.portlandschools.org/smact/)) meeting discussed the [ABLE Act](https://www.autismspeaks.org/advocacy/advocacy-news/summary-able-act). It was suggested that having a speaker present on this at the Coalition would be advantageous. There is a public hearing on Wednesday for the carry-over bill that looks to put the ABLE Act into statute in Maine. [Maine Equal Justice Partners](http://www.mejp.org/) has information on the ABLE Act on their website. [Click here for more information on the ABLE Act.](http://www.maineparentcoalition.org/january-2016-presentation.html)
* [Community Connect Regional Meetings – Save the Date](http://www.maineparentcoalition.org/january-2016-presentation.html).

**Cullen:** At our next meeting on **February 8, 2016,** our featured speakers will be **Neal Meltzer, Executive Director, Waban, and Todd Goodwin, Chief Executive Officer, Community Partners, Inc. Topic: Continued discussion regarding the Section 21 proposed rule changes, including specific examples of funding cuts associated with people affected by the proposed rule changes.**

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).***