May 9, 2016

Minutes

Present: Arthur P. Clum, Jamie Whitehouse, Sally Mileson, Julie Brennan, Meg Dexter, Ed and Suellen Doggett, Perry Blass, Mary Chris Semrow, Mary Lou Dyer, David Cowing, Jennifer Putnam, Patrick Moore, Carrie Woodcock, Cathy Register, Staci Converse, David Lawrence, Peter Stuckey, Patricia Miles, Cullen Ryan, Vickey Rand. Via Zoom – Bangor (UCPofME): Andrew Cassidy, Jon McGovern, Frances Cartier, Jerri Chance, and Kathy Vorenkamp. Sanford (Waban): Morgan Jones. Auburn (John F. Murphy Homes): Darla Chafin and Ann Bentley. 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: Jay Collins, Maine State Independent Living Council (SILC), State Plan for Independent Living (SPIL) Coordinator.** [**mainesilc.org**](http://mainesilc.org/) **Topic: What is the SILC? What is a SPIL?**

**Jay Collins:** Cullen asked that I present to today and provide an overview of the SILC and introduce the SPIL.

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

Jay summarized why the SILC exists, and explained the purposed of the SPIL.

The Maine Statewide Independent Living Council (SILC)is a federally mandated council under the Rehabilitation Act of 1973. The Maine SILC advances independent living by engaging in or supporting research, publication, employment, community organizing, advocacy, and systems reform. Federal statute requires that a SILC be established within a State agency. The statute declares that a Council shall:

* Work with the Director of the [Division of Vocational Rehabilitation](http://www.maine.gov/rehab/dvr/) (as referred to in federal legislation), the [Division for the Blind and Visually Impaired](http://www.maine.gov/rehab/dbvi/), and other councils if required to develop and sign the [State Plan for Independent Living](http://mainesilc.org/state_plan) for the delivery of independent living services to people with disabilities;
* Monitor, review, and evaluate the implementation of the State Plan and communicate with the [State Rehabilitation Council (SRC)](http://www.mainesrc.org/) about activities that address the common needs of specific disability populations and issues under federal law.

The Rehabilitation Act of 1973 was reauthorized by the Workforce Innovation and Opportunity Act (WIOA), which was signed by the President in July of 2014, and went into effect in July 2015. In addition to reauthorizing the Rehabilitation Act, the WIOA includes comprehensive reforms. ([*Click here for more information on the WIOA*](http://www.maineparentcoalition.org/may-2016-presentation.html)*.*) ([Click here for more information on the Maine SILC](http://www.maineparentcoalition.org/may-2016-presentation.html)).

Each Statewide Independent Living Council is required by federal law to submit a State Plan for Independent Living (SPIL). Currently the Maine SILC is in the process of writing its next three-year plan, and is seeking input on developing its goals and objectives. ([*Click here for information on the SPIL*](http://www.maineparentcoalition.org/may-2016-presentation.html)*.*) Maine submits a unified SPIL, which looks at a myriad of different, interrelated individual plans, including those from the Division of Vocational rehabilitation (DVR) and the Division for the Blind and Visually Impaired (DBVI). Part of the development process for the SPIL includes soliciting public feedback. There are various public forums, where anyone with a disability can attend, as well as focus groups where people in the group have a shared experience (i.e. same disability). There is also an online survey for people who are unable to attend a public forum in person. Anyone interested in the public forums or surveys can visit [mainesilc.org](http://mainesilc.org/).

**Discussion:**

-It was stated that policy initiatives are great, and the focus on coordination is admirable. However, where the rubber meets the road, when someone is putting together all of the various pieces for a client it can be very overwhelming.

**Jay:** This is a very good point.I’m looking into how trainings are offered, with the goal of having trainings that establish a shared foundational understanding. People are trained in silos; the SILC could recommend a shared protocol and training expectations.

-It was asked if there is a population on which this has a greater effect.

**Jay:** Historically I would say the needs of people with physical limitations. There has also been some movement for people who are deaf or hard of hearing, or blind or visually impaired. Through needs assessments, whether it’s explicitly indicated or not, it’s become clear that individuals with cognitive disabilities, including ID/DD and traumatic brain injuries, are largely underserved.

-It was stated that the Blueprint for Effective Transition, developed by this group, became part of the basis of legislation to create a commission to study transition. The bill passed both houses during the first legislative session, but died on the Special Studies Table. It was stated that getting this back on the table is imperative.

**Jay:** Due to the transition component of the SPIL, this would likely get circled back to the SILC; we could convene a workgroup within the affected entities, and move past simply having conversations. We’ve had conversations over and over again, instead we need to make a list of activities that have been suggested but haven’t moved forward. I think we need to think creatively regarding moving the conversation differently.

**Cullen:** Jay, thank you; you’ve made something that’s very complicated easy to understand. Well done!

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

**Featured speaker: Arthur P. Clum, Esq. Topic: Affiliation with National Organizations.**

**Cullen:** Arthur wanted to have a dialogue with this group regarding the possibility of having the Coalition become affiliated with a national organization, with the idea of broadening its clout and having increased access to ideas and best practices nationally.

**Arthur P. Clum, Esq.:** There are two advantages to establishing an affiliation with a national organization – information and clout. Regarding access to information, I can provide an example from personal experience. I, along with Peter Stuckey, attended a hearing that OADS sponsored about Maine’s ADA (Americans with Disabilities Act) plan. The hearing was designed to solicit public feedback, though it evolved into focus groups with a national facilitator. The group I participated in felt strongly that there shouldn’t be a cap on the Section 21 waiver. Our facilitator informed us that other states are moving their waivers to section 1915k of the Social Security Act. We discovered that this move would provide the same level of services received under Section 21 and the State would receive enhanced federal reimbursement. Additionally, 1915k is an entitlement benefit which means there wouldn’t be a waiting list for services. After the hearing concluded Representative Stuckey and I further inquired about the 1915k waiver. There are ten states in the process of converting all of their waivers into 1915k, New York and California among them, and Oregon and Maryland have already completed the process. This could be a wonderful opportunity to increase services for all of the waivers, not just for people with ID/DD. In my opinion there seems to be a lot of benefits associated with converting to the 1915k waiver; however, there are potential downsides as well, such as it likely costing the state more money. Additionally, having individual waivers fosters specialization in terms of the different populations served, and that aspect is important. However, providers historically have developed their own expertise, so the expertise is in place possibly eliminating the loss of specialization if we were to move to 1915k. This is a lot of very comprehensive information to digest, but what struck me is that we wouldn’t have had a clue about this if we hadn’t run into someone working on this nationally. An affiliation with a national organization would open the Coalition up to this type of information. There is a lot going on, it’s just a matter of tapping into the expertise and participating in the discussions.

In my mind there are two logical national organizations with which the Coalition could affiliate – [The Arc](http://www.thearc.org/) or [VOR](http://www.vor.net/) (Darla Chafin happens to be the state point of contact for VOR). Initially, The Arc was pro-facility; however, they have since moved away from that philosophy and are pro-inclusion, aligning with the Coalition’s model. VOR has a different philosophy; they believe that a person belongs wherever he or she calls home, wherever that may be. These are two possibilities that I’m aware of, there may be more out there.

As far as clout – in the early days of the Coalition we asked ourselves, “How do we develop clout?” The Arc has entered into class action lawsuits. If the Coalition were to affiliate with The Arc or VOR it would then be an entity that could sue the State, which very much changes the dynamic. I think it’s worth inviting representatives from The Arc and VOR to have them further explain how affiliating would work where the rubber meets the road, such as the cost, what their agendas are, how much would we have to buy into their agendas, etc.

**Discussion:**

**Mary Lou Dyer:** The Arc had a presence in Maine for many years. In the past I deferred to my members who had been members in the provider world. I had the sense that from a provider perspective it didn’t meet their needs on a local level. They agreed that it was important to have national respect and access to information but they thought for the money it wasn’t worth it, for them at least.

**Darla Chafin:** I can talk to people about VOR if they want information. Both VOR and The Arc are good sources for information but you have to remember they have their own agendas.

**Arthur:** I want us to be in the position to tapinto what other states are doing so we can propose things to the Department rather than the Department presenting things to us; to avoid what we went through with the SIS (Supports Intensity Scale).

-It was stated that VOR’s philosophy is counter to what the State of Maine has been working on for years and affiliating with them would be a monumental step backwards. It was stated that it is 2016 and we’re discussing a group that defines itself by a name that is offensive to everyone we represent, and a philosophy counter to our own. There was discussion regarding the difficulty in an organization changing its name, which is likely why VOR has not changed its name to reflect appropriate terminology. It was stated that The Arc has worked diligently to shed itself of what the acronym used to represent (Association for Retarded Citizens), which is why it now solely goes by The Arc. ([*Click here for information regarding The Arc’s name changes over the years*](http://www.thearc.org/who-we-are/history/name-change)*.)*

**Mary Lou:** This is a decision for parents of people with ID/DD in the room. I would like to point out this group has been very well-represented in the Legislature. When Cullen testified this session on Section 17 it was the sharpest testimony he has delivered regarding the Department. People had never heard him speak this way before, as he is well-known for being very collaborative, so it caused them to take pause – if the changes caused him such angst there had to be something there. This group does have clout and you are respected. Everyone worked very hard this year to develop collaborative relationships, united with common goals. When the issue of the rates and the problems with the [Burns and Associate’s](http://www.burnshealthpolicy.com/) proposal came up Senator Brakey stated that if any group knows how to get legislative review it’s the people in this room. I think it’s important to examine what may or may not be lacking. If national information is a gap than there are a lot of ways to get that information, such as inviting people here to present. My hope is that you identify what you think is lacking before jumping into anything. I remember going to meetings when the Coalition was only two years in; just look at the work that you have accomplished – the White Paper, the Blueprint for Effective Transition, raising your voices and advocating effectively in Augusta. The Coalition has worked really well as a group with its partners in state government and I’m not sure we need, at this moment in time, that additional clout.

-It was stated that despite whether or not the Coalition buys into an organization’s entire platform, there is still an association to it and others may presume those values and agendas are shared. Additionally, the Coalition should examine what if anything is lacking. It was stated that over the past year groups that were designed to work in isolation have refused to do so, and instead have worked collaboratively, taking shared action to effect change. This is the mechanism that’s going to buy clout. It was stated that people recently attended the ANCOR ([American Network of Community Options and Resources](http://www.ancor.org/)) conference, and that material from this national conference could make for an informative presentation for the Coalition.

**Cullen:** Unfortunately we don’t have enough time to dive too far into this. I will say that I realize we’ve been here for a full decade as of today. The Coalition started as a group of parents and evolved to include relatives, people with intellectual and developmental disabilities, advocates, service providers, DHHS, Special Education, and experts on Transition, and other stakeholders across the state. We have everyone around the table and try to approach things from the standpoint of collaboration. There are different styles and approaches; this Coalition has been inclusive in nature and friendly in scope. I like that we’ve talked about thinking about what’s missing, and starting from a strengths perspective. Arthur, thank you for bringing this up and for the thoughtful dialogue.

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

**Featured speaker: David Cowing, Parent and Community Connect Member. Topic: Collaborating with OADS to build a stronger system--brainstorming some questions to increase the effectiveness of May's Forums for Individuals and Family Members**.

**Cullen:** The office of Aging and Disability Services **(**OADS) is hosting a series of parent and community forums, holding a handful of them across the state. Despite repeated invitations, OADS has not been at the table for the past few months so we have not been able to participate in an open and inclusive dialogue. David is here today to help us think through what we as a Coalition can do to pull our voices together and make the best use of these forums.

**David Cowing:** The forums look a lot like the forums some of us may have participated in when the SIS was being developed. I attended the Portland forum and attendance was not substantial. Additionally, there were people who were faced with very challenging circumstances, and the majority of the forum was devoted to a small subset’s specific circumstances. The good news is that these individuals had the opportunity to be heard; alternatively, this left very little time for others to raise their voices. With people around this table participating, we could develop a list of topics and ensure that they are heard at every forum. If the Coalition expresses concerns in a coordinated way at each of the forums our feedback will at least be on the record, even if it’s not directly addressed, and we will have the opportunity to be proactive instead of reacting to the Department’s agenda.

**Discussion:**

-It was stated that the Department has been very specific as to the agenda of the forums, though whether or not that will hold remains to be seen. Also, the letter sent to the Department on behalf of numerous parties was not well received and it appears the Department, at this moment in time, has no appetite to work in tandem to help develop the alternative to the SIS. The group discussed the apparent differences between the Coalition, which is a very open, collaborative group, and the Department, which seems to becoming more and more insular. It was stated that as more time has passed without DHHS at the table, it appears that this might be more intentional and coordinated. It was stated that with this in mind, a more assertive approach might be advantageous, and that as long as this group has the reputation for being a collaborative, neutral voice, which it does, it could be a beneficial strategy. The group discussed how it appears the Department has established boundaries around their practices, which requires this group to work to make those boundaries more porous. It was stated that the Department has said they want feedback, otherwise they wouldn’t be holding the forums. With this, the door has been opened a crack, we can push it open by strategically using the forums. Many stated that forums organized by the Department more often than not feel more like lectures than forums in which people can participate.

**Cullen**: I’ve sat in a lot of venues with the Department. It often appears that DHHS comes with a presentation, and after they have delivered their message the allotted time has elapsed. As a process point, this group could turn each one of these forums around and take the floor early on to deliver feedback.

**Peter Stuckey:** This session, you pushed the Legislature to the brink, but you did it with grace. It wasn’t a game or a contest, you just stood up and said what you needed to say. This is what has been remarkable about this group since my very first day around this table – you don’t get distracted by the negativity. Positive energy exudes from this group in a way I don’t think you can appreciate when you’re part of it.

**Mary Lou:** When you’re in a group you don’t realize the power and gravitas you have.

**Peter Stuckey:** When this group first showed me the diagram for the [DD Continuum of Care](http://www.maineparentcoalition.org/dd-continuum-of-care.html) it looked so simple, yet so right. It wasn’t reactionary at all; it was proactive. This group has figured out how to say what you want to say, what you need, in a way that reflects who you are. There’s an authenticity to that that in the political world, which has a strength to it that you can’t push back against. Listening to the conversations today regarding a national affiliation, I think anything you do that brings more knowledge to this group is incredibly worthwhile. However, it’s worth noting that this is what you’ve always done. This group is very adept at gaining knowledge and finding the best manner and means of articulating its message.

**Mary Lou:** I would suggest using the next two years as a time of building, and not expect changes from the executive level. This too shall pass. One of the reasons we developed the White Paper was in preparation for a new regime. The Commissioner of the Department for which the Health and Human Services (HHS) Committee oversees never once came to a meeting this year. One of the efforts this group contributed to was the dialogue regarding the proposed rate changes for MaineCare Sections 13, 17, 28, and 65. This would never have come before the Legislature without the collaborative nature and efforts of this group. My gauge for a legislative session is how much harm came out of it. In my mind, we prevented a lot of harm this year.

**Peter Stuckey:** I’ve sat through eight years of sessions, and the work sessions this group participated in were absolutely the finest, most productive, most penetrating work sessions I’ve ever experienced. You were organized, articulate, and comprehensive; also, the Department wasn’t there which allowed more time for an interactive, robust dialogue. Members of my Committee learned that if you get past the Department taking up an entire work session, there are a lot of affected people who have insightful, valuable contributions to make. The resource you are to the state of Maine is incredible. When you attend the OADS forms, go with this in mind. Provide information hoping, without holding your breath, that some of it gets through.

**Mary Lou:** Be straight forward. Say that we all learned a lot through the SIS process and that we’d really like to share that with the Department in a small working group that starts to look at how an assessment tool works with our PCP (Person Centered Planning) process. We can’t help the Department with system design in a large public forum. Instead, we’re asking the Department to look to this group and the expertise it holds.

**David:** This has been a great discussion and has provided wonderful guidance relating to how we approach the forums. Identifying talking points with this framework would also be beneficial.

**Cullen:** It may be helpful for a small group to meet to brainstorm talking points at some point after today’s meeting. Can I get a show of hands from people who would be willing to connect with David and organize this? *(Many raised their hands).* Perfect, thank you, and thank you David, this was a great discussion.

**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. I have a meeting scheduled to speak with Karen and Gary 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 future meetings.

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

**Cathy Register, Children’s Behavioral Health Services (CBHS):** We are now a fully staffed unit. I brought copies of the CBHS newsletter, which provides an update on what’s happening in the division ([*click here for the newsletter*](http://www.maineparentcoalition.org/may-2016-presentation.html)). One of the major updates I want to share is in regards to Section 28. As you know, the Department used to do central enrollment; we’re not moving back to that, however my division is taking over the waitlist, or the referral list as we’re calling it. This development is very recent, within the last week, so more information is forthcoming. Also, we’re trying to start moving out into some of the underserved communities to expand and build resources.

**Legislative Updates:**

[**Click here for Mary Lou Dyer’s Legislative Wrap Up.**](http://www.maineparentcoalition.org/may-2016-presentation.html)

**Cullen:** I want to take a minute to thank Peter Stuckey for his work over the past eight years. He has worked tirelessly to help the Health and Human Services Committee evolve into a committee that is well-informed. Thank you for your attendance at these meetings, your passion, and your very hard work and dedication.

**Mary Lou:** No one knows how hard Peter worked on LD 475, to increase the Section 29 cap. He worked unwaveringly right up until the very end; it was truly impressive. Thank you for all that you’ve done!

(Large round of applause).

**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.

**Cullen:** At our next meeting on **June 13, 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).***