March 14, 2016

Minutes

Present: Ed and Suellen Doggett, Ann O’Sullivan, Liz Weaver, Kathy Adams, Dee Karnofsky, Mary Chris Semrow, Maura Fay, Amanda Eisenheart, Julie Snook, Patrick Miles, Arthur P. Clum, Sally Mileson, Julie Brennan, Jerry Silbert, Carrie Woodcock, Romy Spitz, Lydia Paquette, Rachel Dyer, John Regan, David Lawrence, Dina Martinez, David Cowing, Tyler Ingalls, Cullen Ryan, Vickey Rand. Via VSee – Bangor (UCPofME): Andrew Cassidy, Jon McGowan, Allyson Cohen, Jerri Chance, Jessica Randall, Francis Cartier, Kathleen Vorenkamp, and Catherine Robertson. Westbrook (Woodford Family Services): Stacy Lamontagne. Sanford (Waban): Morgan Jones. Biddeford (CPI): Meg Dexter and Rory Robb. Winthrop (Autism Society of Maine): Cathy Dionne. Gardiner (Uplift): Mary Lou Dyer. 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: Lydia Paquette, Staff Attorney, Disability Rights Maine (DRM)** [**drme.org**](http://drme.org/)**. Topic: Supported Decision-Making.**

**Lydia Paquette:** Supported decision-making is the concept that we all require support when we make decisions in one way or another. For instance, if I’m going to buy a new car, since I personally don’t know much about cars, before I make a decision I will talk to people in my life that have this knowledge. This is something we all accept as a natural, internalized process. For people with disabilities the same acknowledgement does not occur. For example, when it comes to guardianship the court looks at it as a much more binary process – people make decisions completely on their own or not at all. Supported decision-making reflects that the process should be the same for people with disabilities as it is for people without. Though the support and the frequency may differ, just because someone needs support around a decision doesn’t mean he or she can’t participate; supported decision-making reflects that concept. It is oftentimes talked about as an alternative to guardianship.

It’s easiest to think about supported decision-making in terms of the relationship between parents and children in making decisions. This relationship starts with children slowly gaining responsibility in decision-making, for instance starting to pick out one’s own clothes after having guidance from one’s parents. Eventually children begin to be able to make those types of decisions on their own; the relationship grows and turns into independence. When a child turns eighteen there’s this automatic presumption that something in that parent/child relationship needs to change because legally the child is now an adult. For a lot of people this triggers fear, the notion that they are just going to be left in the world on their own. However, this isn’t reflective of the community process of adulthood. I was not left in the world on my own when I turned eighteen, and there were decisions I continued to make with my parents. Specifically, I signed away the rest of my life in student loans but every part of that decision was made with my parents by my side. This is an example of supported decision-making; however, because I’m a person without a disability that relationship was accepted and supported by the community. Participating in decisions that affect one’s life is a process that is just as important for people with disabilities. When someone turns eighteen decision-making doesn’t have to become a binary process; people don’t have to forego all of their supports and their parents can still be involved. Supported decision-making reflects the idea that this relationship can and should continue, that the individual should have a voice in the process, be able to express the things that makes him or her happy, and be able to live a fulfilling life. When someone takes away all of a person’s authority and decision making, which happens through guardianship, he or she cannot participate in the decision-making process; the rest of the world won’t include the individual and will look solely to the guardian. All of that continual growth that has been made throughout one’s life in supported decision-making is gone.

There’s been a lot of research behind supported decision-making and the effect, good or bad, that it has on people. There has been significant research around abuse; the findings have been that people under guardianship are more susceptible to abuse. We usually think of guardianship as the most protective option, but what often happens is that people, because they’re now looking to someone else to exclusively make decisions for them, don’t speak their mind. People are used to someone prescribing what to do, and thus develop the inability to make decisions on their own. People participating in supported decision-making can more effectively communicate in instances of abuse because they are accustomed to having a voice in matters that pertain to their lives. The concept of supported decision-making is easier to think about it in terms of a parent/child relationship; it’s much more abstract and harder to think about it in terms of someone without that natural support.

I brought business cards today because I wanted everyone to have my contact information in case anyone had additional questions. Please feel free to contact me! *(Phone: (207) 626-2774 ext. 210; email:* [*lpaquette@drme.org*](mailto:lpaquette@drme.org)*).* Additionally, we are trying very hard to find community partners, people who are interested in this concept and want to know more. [The Supported Decision-Making Coalition](http://supportmydecision.org/) meets quarterly, with email communication occurring more frequently. At the quarterly meetings we have an opportunity to hear what’s going on in other states. If anyone is interested in joining please let me know.

I have also brought what’s called a [Designation of Supported Decision-Making Team Form](http://www.maineparentcoalition.org/march-2016-presentation.html). This is a way to document that someone is in a supported decision-making relationship. The form is a template. I recommend that if someone wants a more individualized agreement they come to me, we can discuss it, and I will draft it for you.

Also, to the extent that there’s anyone interested in scheduling a training I have a two-hour lecture style training as well as a roundtable discussion training. [Pine Tree Society](http://www.pinetreesociety.org/default.asp) is hosting a roundtable discussion with me this month and they’re inviting parents who are interested. There is also an upcoming webinar *(*[*click here for more information*](http://events.r20.constantcontact.com/register/event;jsessionid=B7D791A3AB7DB2CA5C4E7746EC57A380.worker_registrant?llr=iswi7yiab&oeidk=a07ecdongyd994bd1f2)*).*

**Discussion:**

-It was asked if supported decision-making could take the place of guardianship. It was also asked if it could replace a Rep Payee, which can be costly.

**Lydia:** Supported decision-making can apply anywhere; it can apply to someone who is already under guardianship, it can replace guardianship, and it can be practiced before someone turns eighteen. It can really be an alternative to anything that it would work for, including a Rep Payee. It puts into practice the notion that the relationship isn’t binary, and it’s reflected to the community so professionals know who is involved in decision-making. If a person is able to make decisions with support, even if it’s significant support, than supported decision-making is applicable.

-The group inquired about having access to the research Lydia mentioned.

**Lydia:**  I would be happy to distribute the research ([*click here*](http://www.maineparentcoalition.org/march-2016-presentation.html)).

-It was asked if the designation of supported decision-making team form would meet various provider regulations.

**Lydia:** What’s required for HIPAA (Health Insurance Portability and Accountability Act) is an acknowledgement that the person wants the information released, so the form should suffice; however, you may end up having to sign the agency’s release as well depending on individual agency policies.

-It was stated that the University of Maine, Orono has a lot of information on connecting with parents around students with disabilities, and that some of that documentation might be advantageous to analyze.

**Lydia:** Thank you for that information. [The University of Maine Center for Community Inclusion and Disability Studies](https://ccids.umaine.edu/) has been helpful with drafting language as well.

-It was asked if Lydia could elaborate on different types of decisions – beyond medical and financial.

**Lydia:** We make numerous types of decisions across the course of our lives; major decisions relating to medical care, housing, finances, etc. We make significantly more decisions than those on a daily basis – what we eat, where we go, who we hang out with. When someone acquires full guardianship they have the authority to make decisions over everything, and it’s very rare that I’ve spoken to a guardian who intended to have control over everything. More often people are looking for a say in those major decisions and unknowingly end up with far more control. However, what might be more ideal, and what the guardian was likely intending, is having the individual make day-to-day decisions autonomously and the major decisions through supported decision-making.

-It was asked if supported decision-making was included in the guardianship guide developed by Vanessa Bell and the Muskie School.

**Lydia:** They will be updating it to include supported decision-making.

**Cullen:** Thank you very much, this was very informative!

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

**Featured speaker: Rachel Dyer, Associate Director, Maine Developmental Disabilities Council (DDC)** [**www.maineddc.org**](http://www.maineddc.org/)**. Topic: Section 29 toolkit and overview of DDC goals.**

**Rachel Dyer:** The Maine Developmental Disabilities Council (DDC) is a partnership of people with disabilities, their families, and agencies which identifies barriers to community inclusion, self-determination, and independence. The Council acts to effect positive change through advocacy, training, demonstration projects, and support for other inclusive and collaborative systemic change activities.Because we are federally funded, we have to write a five-year plan. Part of that process is soliciting feedback from people to see if we got it right. What I have distributed to the group is the plain language version of the plan, with goals and objectives. I would love to collect written feedback to see if this fits with what’s going on for folks with intellectual/developmental disabilities (ID/DD).

**Begin Presentation.** [Click here for the Maine DDC State Plan Synopsis and the Public Feedback Form.](http://www.maineparentcoalition.org/march-2016-presentation.html)

**Rachel:** I also wanted to pass on information regarding our Small Grants Program *(*[*click here for more information on funding opportunities through the Maine DDC*](http://www.maineddc.org/funding-opportunities/)*).* Essentially we’re looking for grant submissions until we’re overrun with applications, so please send them in! Kim Humphrey’s waiver advocacy training was part of our Small Grants Program; Diane Boas’ Community Support Toolkit, MaineCare Section 29 Edition (Section 29 Toolkit) was as well.

With the Section 29 Toolkit, Diane wanted to find a way to measure the quality of services people receive. Now that the Section 29 Toolkit is complete, a Section 21 Toolkit is in the pipeline. Before we launch into that, we thought it best to determine how the toolkit works in practice. I am distributing copies of the full toolkit. It is on our website in a format where you can navigate easily to different sections or you can download the entire toolkit [(click here for information on the Section 29 Toolkit.](http://www.maineddc.org/section-29-toolkit/)) We are looking for people who are willing to test this in a structured way and provide substantial feedback. ([Click here for the Section 29 Toolkit Feedback Flyer](http://www.maineparentcoalition.org/march-2016-presentation.html).)

**Cullen:** Relatedly, the Center for Community Inclusion and Disability Studies has someone who is working with us to create a timeline, similar to the information in the toolkit, in a very user friendly layout. This is geared towards parents who may not know anything about the system and how it works. It’s meant to truly be a timeline, including action steps, covering one’s lifetime. It’s currently being fine-tuned and should be ready in a couple of months. The goal is to make it very easy for people to know how the system works and this will be one tool of many that should help. We’re very excited to unveil it to the Coalition when it’s finalized.

**Discussion:**

-It was asked how the toolkit is being promoted.

**Rachel:** We have iton our website and it is linked on the Coalition website. We presented it at the Autism Conference on Saturday as well.

-Many people stated that they would be happy to send it to their distribution lists.

**Cullen:** Thank you Rachel, this is fantastic!

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

**DHHS Update:**

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

**Cullen:** I heard from Karen Mason this morning and she stated that they’re unable to have anyone from the Office of Aging and Disability Services (OADS) in attendance today, and that she would be back in touch regarding the Department’s future attendance. Everyone around the table is in agreement that it is important to have an interactive dialogue between the Coalition and the Department. I am hopeful that they will be able to attend next month.

**Legislative Updates:**

**Cullen:** First and foremostI want to thank everyone who is part of this Coalition. Last week was a monumental week where we were able to effectively raise our collective voices, which led to a big response from DHHS and the Health and Human Services (HHS) Committee. Representative Peter Stuckey is unable to attend today but asked that I pass along his appreciation to this group as well. He stated that what has occurred over the past couple of weeks has been a showing of terrific advocacy, and that he has never seen anything quite like it.

Over the past few weeks this Coalition has been part of successfully petitioning for legislative review of the Section 21 proposed rules, and participated in a robust public hearing in front of the HHS Committee, where 80 people testified and turnout was so great that the HHS Committee overflowed into two overflow rooms. Additionally, throughout last week the Committee heard from folks on Tuesday, where LD 475, the bill introduced by Representative Stuckey to increase the Section 29 cap from 20 to 40 hours per week, was considered and voted 6 to 2 Ought to Pass As Amended, with the amendment proposing to add $5 million for the Section 21 waiting list. This was a result of us showing up and raising our collective voices. Then, on Friday the Committee held its third work session on the Section 21 proposed rule changes and in a unanimous decision of all present voted to make any rule change to Section 21 “major substantive.” Major Substantive would mean that when DHHS develops its next proposed rule changes they would go to the HHS Committee for a public hearing prior to being finalized. This would allow an opportunity for more eyes to look at whatever DHHS proposes and an opportunity to testify and educate Legislators about how what is proposed might affect you, as so many of you did very eloquently at Monday’s public hearing. A lot of the testimony was very personal, illustrating what goes on in our family members’ lives, what each day is like, and why it’s important to have services work a certain way. Many people also expressed the importance of DHHS opening this up to be an inclusive and transparent process. I think the HHS Committee heard that part. Hopefully this will act as a catalyst to a new design that includes all of us in the decision making.

In addition to members of the Coalition, I wanted to thank Community Connect and MACSP ([Maine Association for Community Service Providers](http://meacsp.com/)) as the efforts demonstrated last week took a lot of time, energy, and hard work. Importantly, I also want to thank the HHS Committee who went to great pains to understand and respond to this complicated issue. During this legislative session the Committee has been extremely generous with its time. Members of the Committee listened intently and heard us well. I wanted to take to the time to express immense gratitude for their thoughtful consideration; not all HHS Committees have been this engaging and responsive, and this is a pivotal time for them to do so.

**Mary Lou Dyer:** The HHS Committee is reviewing the amendment to LD 475 tomorrow afternoon, then it will go to the House, the Senate, and then the Appropriations Committee before going to the Governor. Tomorrow there is also a hearing at 1pm regarding establishing a commission to look at direct care workers, including workforce issues that have been expressed by this group.

**Cullen:** We’re several steps out from anything being finalized, but there will be several opportunities to raise our voice as the Legislature is still in session for about another month. Be on the lookout for action alerts regarding opportunities to take action.

**Mary Lou Dyer:** I wanted to add that it has been a very exciting year. One of the nicest things that happened last week, Representative Hymanson said to the full group that was still there Friday afternoon that the petition for legislative review was one of the best examples of democracy at work that she had ever seen. This truly is an exciting and important period of time. It is remarkable to see how people who care about services and supports can work together collaboratively to effect change.

**Cullen:** Last week’s efforts were related to MaineCare, specifically the Section 21 proposed rule changes. DHHS released proposed rule changes that are equally dramatic for other MaineCare sections. This past fall we discussed the proposed rule changes for Section 17, however only recently the urgency and level of severity came to light. Section 17, which provides services for people with Serious and Persistent Mental Illness (SPMI), was one of the mechanisms of compliance for the AMHI (Augusta Mental Health Institute) Consent Decree. There are five clear ways folks can present with psychotic symptoms: Schizophrenia, Schizophreniform, Schizoaffective, Bipolar, and major depressive disorder with psychotic features. It is also possible with PTSD (Post Traumatic Stress Disorder), or some personality disorders. In its proposed rule changes, DHHS essentially chose two of the five, Schizophrenia and Schizoaffective disorder, as eligible diagnoses for Section 17 services. The proposed rules do include a mechanism for including these other diagnoses as eligible for services, but the process and documentation needed is potentially cumbersome. This is very concerning as it could result in many individuals being discharged from needed case management services and people currently housed with a BRAP (Bridging Rental Assistance Program) voucher could lose their subsidy. How does this affect you and your loved ones? There is a portion of people with ID/DD who are dually diagnosed with a mental illness and are served either by both Section 17 and Section 21, or Section 17 while on the waitlist for Section 21. The new eligibility criteria could make those folks with ID/DD and presenting with psychotic symptoms ineligible for Section 17 services. The rule changes are scheduled to take effect on April 8, 2016. I would like to encourage the Coalition to take action. A petition is being circulated that will be delivered to the Senate, House, and the Governor. Signing the petition is very simple and takes very little time. MACSP is taking action, as well as service providers in the mental health field. [Click here to access the petition regarding the Section 17 rule changes.](http://petitions.moveon.org/sign/restore-mainecare-section.fb48?source=s.fb&r_by=2042185)

**Housing Updates:**

**Cullen:** The President released his proposed FY 17 budget, which includes slight increases for Section 8.I was in Boston on Friday meeting with the New England Housing Network and the word from Washington is that the current strategy is not to talk about curing sequestration, which caused devastating cuts to programs such as Section 8, but to instead talk about new funding. The President is proposing adding new money to Section 8 as part of his budget proposal. Currently it’s unclear how Congress will receive his budget. In Maine, the HUD Section 811 program is still moving along well, with an anticipated start date in May. More to follow next month. We will also learn more about how the National Housing Trust Fund will work in Maine this spring.

**SMACT:**

There was a SMACT meeting March 4th which featured a presentation on Section 18 and Section 20. Next month’s meeting, on April 1st, is scheduled to include a presentation from Emily Kalafarski, Waiver Manager for OADS, on Section 21 and Section 29.

**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.

**Other Updates:**

**David Cowing, Community Connect:** There is great synergy happening right now. We’re trying to set up satellite sites to expand the work that happens around this table. Meetings are focused on what concerns families locally. It truly has been a great effort and will establish a two-way street – we can bring the Coalition to other areas, and bring local issues back to the Coalition. [Click here for the Community Connect map that shows the cities and towns in Maine where citizens signed the support petition for legislative review of the Section 21 proposed rule changes](http://www.maineparentcoalition.org/march-2016-presentation.html).

-It was asked if Community Connect has a website or a Facebook page.

**David:** Currently Community Connect materials are being posted on the Coalition’s website.

**Cullen:** At our next meeting on **April 11, 2016,** our featured speaker will be **Karen Mason, Associate Director, and Emily Kalafarski, Waiver Manager, Developmental Services, Office of Aging and Disability Services, DHHS.**

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).***