September 14, 2015

Minutes

Present: Ed and Suellen Doggett, Irene Mailhot, Mary Chris Semrow, David Cowing, Maura McDermott, Debbie Dionne, Katrina Ringrose, Brian McKnight, Lebrun Joseph, Sally Mileson, Julie Brennan, Carrie Woodcock, Patrick Moore, Dina Martinez, Luc Nya, Inga Sullivan, Sue Murphy, Wendi O’Donovan, Valerie Smith, Robert Duranleau, Jaime Hoar, Kim Humphrey, Rebecca Emmons, Laurie Raymond, Rachel Dyer, Liz Weaver, Peter Stuckey, Annemarie Salzberg, Cullen Ryan, Vickey Rand. Via VSee – Bangor (UCPof ME): Andrew Cassidy and Tracy Beauregard. Biddeford (CPI): Todd Goodwin. Sanford (Waban): Selena Brock and Bobbie Santos. Auburn (John F. Murphy Homes): Ann Bentley and Darla Chafin.

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.

**Featured speaker: Liz Weaver, Project Manager, Dementia Capable Service Expansion, Southern Maine Agency on Aging (SMAA)** [**www.smaaa.org**](http://www.smaaa.org/)**. Topic: Southern Maine Alzheimer’s Disease Initiative (ADI) Grant.**

**Liz Weaver:** I grew up in western Maine and have worked with older adults for my entire career. I have been a caregiver myself for most of my life. I am one of nine children. My mother had cancer, and my step dad had vascular dementia – perhaps Alzheimer’s, we were never sure. Another piece of my background is that my sister, Susan, is profoundly developmentally disabled. Before too long it became apparent that something seemed to be amiss. She was later diagnosed as having ID/DD, but it was at a time when not much was known. They knew it was not Down syndrome, but her capabilities were similar. She lived at home until she was eight, but had the needs of an infant. It became too much to handle. Susan went to live at Pineland when she was eight. This was traumatic for the entire family. The ripple effects of grief and guilt are still there, so much so that I realized while talking with Cullen that I have processed a lot of other care giving but this one I haven’t. As a family we didn’t talk about it. Our first visit to Susan was at least six weeks after she was admitted to Pineland, as we were not permitted to go sooner. We discovered that she was not being bottle fed despite her not having the capacity to drink out of a cup. Those first weeks were traumatizing for everyone. However, she benefitted from incredibly loving and wonderful caregivers. They worked very hard to take care of her. Susan was one of the last people to leave Pineland. She was admitted to a small group home built especially for her and three other people. At this point I was her co-guardian, along with my mother. I was very fearful of this next step. At least we knew what was happening at Pineland. The unknown is frightening. However, it has created a much more enriched life for her. I’ve watched the pendulum swing over the years. The emphasis on PCP (Person Centered Planning), as wonderful as it is, has had some interesting issues. People were being unrealistic in what she can do and in what they were actually seeing. Ultimately I asked them to explain what “participate” means, as it was documented that Susan was “participating” in activities higher than her capabilities. The response was that she observed and seemed to enjoy it. This made her abilities seem greater than what they actually were. People want to be such cheerleaders that they’re saying things that are not literally true. It’s not a denigration to say that someone can’t do something. My mother and I started to receive cards and letters written in the first person, “from” Susan. Her staff didn’t understand why that was so upsetting and it reopened trauma for my mother who said “they think she’s a doll or a puppy. They don’t know what she thinks.” It’s not respectful. There have been a lot of ups and downs, but overall she has received wonderful care and I’ve been happy with that. It is difficult to care for and advocate for someone in particular situations; this is true for people with dementia. They often can’t express their needs, or that they’re in pain, or that sitting in a chair a certain way is painful. They are labeled as resistant or combative.

**Begin presentation.** [Click here to view the presentation.](http://www.maineparentcoalition.org/september-2015-presentation.html)

**Liz:** SMAA doesn’t have the same depth of knowledge in intellectual disabilities (ID). We want to have more capabilities across all of our programs and services. We recognize that people with ID are aging. People with Down syndrome are most vulnerable for dementia and Alzheimer’s. Individuals with other intellectual disabilities are vulnerable in the same way we all are, plus there are more co-morbidities, instances of heart conditions, diabetes, strokes, and being on heavy psychotropic drugs. These all compromise the brain. The shift from habilitation in the ID service world – a system focused on incrementally gaining skills, having goals, and new learning – to rehabilitation in regards to dementia is a big one. When you have dementia habilitation is not possible anymore. Skills will decline, this will happen as a function of the disease. Rehabilitation allows individuals to maintain their best ability to function at any given time. There is still a lot that can be done, but it is a paradigm shift. These are learnable things and there’s still a lot of joy and a lot of meaningful life.

In general, all people with Down syndrome will eventually develop the hallmarks for Alzheimer’s. However, not everyone will go on to express dementia because of it. By age 40, 25% of people with Down syndrome will show symptoms of dementia; nationally, the estimate for all individuals under 65 is 4%. These percentages increase as people age.

SMAA has two adult [day centers](http://www.smaaa.org/adc.html), the [Stewart Adult Day Center](http://www.smaaa.org/adc-stewart.html) in Falmouth and the Truslow Center in Saco – soon to be replaced by a brand new center in [Biddeford](http://www.smaaa.org/better-day-biddeford.html). People who attend either center need to be people who have dementia. We have been asked if we can take young adults with intellectual disabilities. We don’t because it’s mixing apples and oranges, and two age groups that are hard to mix. The centers are dedicated to dementia. Our [Family Caregiver Support Program](http://www.smaaa.org/family-caregiver.html) serves caregivers of any age caring for a person who is 60 or older. We don’t have extensive knowledge regarding the kinds of support that caregivers might need; we have education programs and all kinds of other things but we need to know more. The [Allen Cognitive Assessment](http://www.crisisprevention.com/Resources/Knowledge-Base/Cognitive-Assessment-Tools) is a great assessment tool and staff will be assessing members over the next couple of months – it will be part of our protocol. It is important for anyone with dementia to be looked at as someone with positives, strengths, and abilities. The assessment allows us to get a realistic picture of who the person is, what they can do, and things they’re going to have difficulties with.

We are trying to expand our own knowledge across all programs. Half of our Meals on Wheels volunteers are people with ID – with support they are able to deliver meals, it’s terrific. We value this, but we realize that site managers don’t know much about ID, and they should. We want to broaden our awareness and break down silos between the aging community and ID community. Both speak different “languages” with numerous acronyms and different funding sources. Ultimately, I’m charged with creating a sustainability plan for when the ADI grant ends, which will involve 3rd party payers. I should note that there is no funding for direct services through this grant, but it will go a long way in providing education. Efforts are underway to develop a comprehensive curriculum of care for providers of ID and dementia. We have been rolling that out over the last nine months or so. We are working to offer this to our staff and other staff who are interested and need that information. We are developing a component with family caregivers as well.

**Discussion:** The group discussed baseline assessments prior to being symptomatic for people with a higher chance of showing signs of dementia.

**Liz:** The [National Task Group on Intellectual Disabilities and Dementia Practices](http://aadmd.org/ntg) is a huge national consortium that looks at this subject. They’ve developed a [screening tool](http://aadmd.org/ntg/products) that they recommend families and physicians use. The tool helps you know the things to look for, and provides a snapshot that can be looked at and compared over time. The [Geriatric Evaluation Clinic](http://www.mmc.org/geriatric-assesment-clinic) at Maine Medical Center see people with ID, though they are mostly coming from group homes. They do their best to perform assessments but it is easier if there have been a baseline assessment and subsequent periodic assessments.

The group discussed the need for guidance for adult case managers in the disability world to navigate the aging community on behalf of clients. Rehabilitation versus habilitation is completely different. Case managers are struggling for this populations because they can’t meet their needs. Additionally, it is difficult to ensure there are no missteps with different funding streams. It was stated that the private pay option is always available, however, there should be every attempt to exhaust any insurance that is available.

**Liz:** Medicare doesn’t pay for day services at the adult day centers; however, Section 19 does cover it. My suggestion around this would be to call Polly Bradley, Director of Adult Day Services. She can be reached by calling our main number: 207-396-6500.

It was stated that it would be very helpful to outreach churches and synagogues with this information. Family members often go to church or someone from the church is connected to the family. The group also suggested contacting Fire/EMS, as they know frequent utilizers of services.

The group discussed [Goold Health Systems](http://www.ghsinc.com/) performing assessments, and asked what tool they use. It was stated that Goold uses the MED ([Medical Eligibility Determination](http://www.maine.gov/dhhs/oads/aging/long-term/assessment.shtml)) Assessment. One determining need is how much support is needed for activities of daily living.

**Liz:** I need to reacquaint myself with Goold; however there are people at the office that know this inside and out!

A parent stated that her daughter has Down syndrome and was diagnosed with sleep apnea, despite having already addressed medical recommendations to decrease her likelihood of developing it. The group discussed how this methodology would also work well regarding dementia.

**Liz:** This is very true. It is always wise to get a complete medical work up. There are conditions that can mimic dementia and those are treatable conditions, but sometimes you have to look hard to find them.

**Cullen:** Thank you for your very insightful presentation. I want to specifically thank you for sharing your story and personalizing this for all of us.

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

**Featured speaker: Rachel Dyer, Associate Director, Maine Developmental Disabilities Council** [**www.maineddc.org**](http://www.maineddc.org/)**. Topic: National Core Indicator Results.**

**Rachel Dyer:** The [Nation Core Indicators](http://www.nationalcoreindicators.org/) (NCI) are well researched, standard measures used to assess the outcomes of services provided to individuals with developmental disabilities. They compare what’s going on in developmental services in a state and between states. The more states that participate the better the data and the more meaningful the responses will be. To take the survey individuals had to be receiving case management services and one other MaineCare service. It’s a random sample of all eligible people. I am going to provide a brief overview of what we saw in the first year. There are also full state reports ([click here](http://www.nationalcoreindicators.org/states/ME/)).

**Begin presentation.** [Click here to view the presentation.](http://www.maineparentcoalition.org/september-2015-presentation.html)

**Discussion:** It was asked what happens when an individual doesn’t understand a question. The survey was designed to be reliable and valid for people who are non-verbal. The first section is answered by the participant, but the second part can be answered either by the individual receiving services or an informant (someone who is not the case manager). The interviewers’ feedback was that most people could indicate yes or no responses. The questions are not complex.

There was discussion regarding the safety question. It was stated that for individuals in group homes it is not uncommon for someone to feel unsafe because another person in the home is having an episode. There are also individuals with low frequency, high intensity behavior, and without adequate staff there can be physical attacks. These outliers are sometimes forgotten.

The group discussed how DHHS, OADS ([Office of Aging and Disability Services](http://www.maine.gov/dhhs/oads)) is using the NCI results and if there is any tie-in to the Olmstead plan. OADS is also in the process of analyzing the data and attempting to loop it back into some of the planning. The NCI is more of a snapshot, and Rachel was not aware of any plans to use the NCI as a way to measure the HCBS (Home and Community Based Services) rule.

**Rachel:** People can email me with questions or other things that we should take a closer look at as a group.

**Cullen:** Thank you Rachel, this is great! It is wonderful to have you back again to present on this.

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

**DHHS Update:**

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

**Waitlist Numbers:** Currently, the number of people on the wait lists are: Section 21 – 1178, Priority 1 – 0 (all have pending offers, there are no individuals waiting to be offered services), Priority 2 – 425, Priority 3 – 753. Of the 1178 people waiting for Section 21 but already receiving or have a pending offer for Section 29 – 1015. There are 372 Section 29 offers out currently that have received no response. If you know someone who has received an offer please contact your resource coordinator. Generally, people have 60 days from the notification letter and 6 months to start the service. If people do not contact us the Department will be sending letters notifying that they will be removed from the list and will have to reapply for the service. All case manager should know about the offers that have gone out because notes were put into EIS. Also, the Department has hired Emily Kalafarski for the Waiver Manager position, Bridget’s former position.

**Cullen:** We will send a reminder about the Section 29 offers with the minutes as this is very important.

**Discussion:** It was asked how often people fall off, or fall out, of the service. Additionally, it was asked what will happen to individuals who signed up for Section 29 after 6/30/15.

**Brian:** Generally it is hit and miss with regard to people falling off the service. We should be tracking that. Now that we are able to offer more services for Section 29 we’ll be tracking it more closely. Applications are being processed for individuals that signed up for the service after 6/30/15. We’re not sure in what manner they will be able to continue to offer services; it depends on how many of the 372 accept the offers that are currently pending. The goal is to avoid another waitlist. The Department is keeping track of all of the application and the dates when they come in.

**Cullen:** The clearing of the Section 21, Priority 1, and Section 29 waitlists that occurred this past spring/summer was very impressive. However, we didn’t have any waitlists before all that long ago. I hope the Department is taking special consideration regarding how long it takes the system to react to service offers, and that the Department refrains from reacting quickly or rashly. I know a lot of vendor calls have gone out and the pace has been dizzying. Clearing the waitlists threw a lot of people into a system that wasn’t quite ready for it.

**Brian:** I don’t think the Department is going to do that. Also, OADS is working on a case management care coordinator training for spring 2016. There were also a well-attended direct support professionals training and Gary was there for the opening remarks.

The group discussed Section 21 priority 2 and 3 offers, now that the priority 1 waitlist has been cleared.

**Brian:** With the priority 1 list cleared we are going to priority 2. We have to keep some offers in reserve for people who may be out of state and in other situations that may develop. Generally we are able to make five offers per month for individuals on the priority 2 waitlist.

There was discussion regarding the prioritization that has been discussed at the past few meetings. At previous meetings both Brian and Karen stated that they were starting to look at other criteria for prioritizing the order in which individuals on the priority 2 waitlist receive offers in order to serve the ones in most need. It was also asked if the criteria would be made public.

**Brian:** The department is conscious of aging parents, and increasing medical issues and is working on establishing criteria in order to serve those most in need. I don’t believe that the criteria is public at this point.

**Representative Peter Stuckey:** The five offers per month, is that the new norm? Some funding for Section 21 was included in the biennial budget, amounting to a little more than $7 million, which will allow approximately 200 people to be offered Section 21. Has this new money been spent? Is it reserved?

**Brian:** It is still reserved, and we anticipate being able to make 200 additional Section 21 offers. The Department is looking into whether all 200 offers should go out at once, or whether the offers should be spread out across a number of months. A decision hasn’t been made yet.

**Representative Peter Stuckey:** Is the Department having discussion regarding the annual influx of new individuals coming in, in terms of keeping the priority 1 waitlist at bay?

**Brian:** Yes, this is one of the things that is being tracked and the Department will be discussing it with the Legislature. We want to be able to make offers to those people as well.

It was noted that some providers are ready and able to start providing services, however some are not good matches for individuals and their needs could not be met. It was asked how the process for finding service providers is working when this is occurring.

**Brian:** When a vendor call goes out there is very limited information that can be provided. In order to get more information the agency would need to make that contact and have those conversations with the case manager.

Some felt that it is OADS’ responsibility to assess that need. The Department has the SIS and other tools but the data isn’t being used. It was stated that the SIS rules had to go to CMS ([Centers for Medicare and Medicaid Services](https://www.cms.gov/)) for review. CMS sent a request for additional information that was completed by the Department. The rules have gone to the Attorney General’s office, then they have to go to the Commissioner’s office, the Governor’s office, and then go out for public hearing. SIS data hasn’t been used yet due to this process. Additionally, individuals may want and choose shared living options, and there might be a match that could let that happen even if one provider/agency isn’t a good fit. It is important to not carve out cut and dry options for people – consumer choice is important.

**Legislative Updates:**

**Representative Peter Stuckey:** We worked hard to ensure resources and commitments were made and I am anxious to hear progress reports on those matters – what is working, what isn’t working, where we can improve, and so on. The [Health and Human Services Committee](http://legislature.maine.gov/house/jt_com/hum.htm) is interested and committed to understanding all of that.

**Housing:**

**Cullen:** On the federal side,Congress was on break for the month of August. There will likely be a flurry of activity now, and then very little activity the following year due to the Presidential election. The THUD (Transportation-Housing and Urban Development) Appropriations Committee in the House and Senate had vastly different proposals. The Senate THUD bill kept fairly adequate funding for many programs but wiped out an entire program, the HOME program, a key . The House bill cut many programs and diverts funding for the National Housing Trust Fund into the HOME fund, while still providing a heavy cut to the program. They will have to come together before the end of September, or we will be faced with a federal government shutdown and the full effect of sequestration. Congress will likely kick the can down the road with a Continuing Resolution, which would keep the government open but keep the current levels of funding, which is inadequate and will not cover grant renewals for Section 8. The good news is that our delegation is well informed of our needs.

**Question:** I have heard that there are drastic proposed cuts to SSDI beginning in 2016. Do you have more on this?

**Cullen:** I will research this and bring what I find out to the Coalition.

*(*[*Click here for an article with information on the proposed Social Security Disability benefit cuts*](http://www.nytimes.com/2015/07/23/us/disability-benefits-face-cuts-in-2016-trustees-say.html)*)*

**Update on the DD/ID Continuum of Care**

**Cullen:** We have changed the focus of the discussions to better cater to the purpose.The purpose of this group is to be a think tank for the department, to draw on stakeholders’ knowledge to think about things such as quality of life and how to make the system work the best as changes and initiatives are implemented.

**SMACT (**[**Southern Maine Advisory Council on Transition**](https://www.facebook.com/someadvisorycouncilontransition)**):**

**Annemarie Salzberg:** The first meeting this year is Friday, 10/1 and will feature a presentation is on the SIS. Also, the next Pathways to Transition fair will be on Thursday, 10/22. [Click here for the flyer](http://www.maineparentcoalition.org/september-2015-presentation.html).

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

**Katrina Ringrose:** The [Maine Developmental Disabilities Council](http://www.maineddc.org/) helps guide the work we do as advocates. We are always looking for people who are interested in joining us.

**Other Business, Announcements:**

* [Specialized Housing announcement regarding a second Maine program similar to 20 E Street](http://www.maineparentcoalition.org/september-2015-presentation.html)
* [MaineHousing Section 811 Information/Memo regarding rental assistance for individuals with disabilities](http://www.maineparentcoalition.org/september-2015-presentation.html)
* The MDSOAB ([Maine Developmental Services Oversight and Advisory Board](http://www.mainedsoab.org/)) will be hosting a series of forums. Information is forthcoming. MDSOAB is also looking for feedback regarding how the system is working and what the service needs are. [Click here for the Public Feedback Forum Individual Survey](http://www.surveygizmo.com/s3/2318934/Public-Feedback-Forum-Individual-Survey-2015).
* Workshop, 10/13 – Healthcare and Effective Care Management for Persons with ID/DD. [Click here for more information](http://www.mainequalitycounts.org/articles/46-1138/oct-13th-workshop-healthcare-and/3).
* There is a campground available for rent. This could be a prime location for a collaboration of schools to get together, apply for grant funding, and use it as a site to develop job skills for people with disabilities. Formally the campground was a farm, it is on a lake, and is approximately twenty minutes outside of Portland.

**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 be right in 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!

**Cullen:** At our next meeting on **\*\*October 19, 2015\*\* (third Monday),** our featured speaker will be **Mike Charley, IBIS Remote Monitoring. Topic: Virtual Telemedicine.** Also featured will be: **Mel Clarrage, Chair, State Independent Living Council (SILC). Topic: Three Year State Plan for Independent Living.**

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

***Burton Fisher Community Meeting Room, located on the First Floor of One City Center in Portland***

***(Off of the food court).***