October 19, 2015

Minutes

Present: Julie Snook, Arthur P. Clum, Brian McKnight, Ed and Suellen Doggett, Jennifer Putnam, Maura McDermott, Julie Brennan, Sally Mileson, Todd Goodwin, Betsy Morrison, Beth Mylroie, Mike McClellan, Mel Clarrage, Cathy Register, Jaime Hoar, Kim Humphrey, Lisette Belanger, Peter Stuckey, Irene Mailhot, Staci Converse, David Cowing, Laurie Raymond, Gerald Silbert, Piali De, Mike Charley, Cullen Ryan, Vickey Rand. Via VSee – 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: Piali De and Mike Charley, Senscio Systems, IBIS Remote Monitoring** [**www.sensciosystems.com**](http://www.sensciosystems.com/)**. Topic: Virtual Telemedicine.**

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

**Piali De:** [IBIS Remote Monitoring](http://www.sensciosystems.com/ibiscare-overview) provides a clinical safety net for someone with complex health issues. IBIS will enable someone to live in as independent of a setting as is practically possible. It is designed to reduce emergency room visits, days spent in the hospital, and delay transition to institutional care as long as possible. The technology is very person-centered. We have all watched parents age and lose their ability to self-manage. The technology began with elder care in mind. Through our work in South Dakota we realized that this technology has a place, and fills a need, in the ID/DD and mental health community. We went to South Dakota to be part of the elder care community. We recognized the technology is so easy to use and could benefit children with disabilities. We got connected to the support community in South Dakota to use the technology to create a seamless transition – following a child, who cannot self-direct, as they transition into the adult care community. With IBIS there would be continuous health data from childhood to adulthood, bettering the continuity of care. Data is reported by the person using the system, and a lot of data is passively collected. IBIS interprets movement for signs of depression, anxiety, straying from protocols, and so on. IBIS analyzes data in real time to be able to detect problems and hand off to the right care giver to address the problem in a timely fashion. This allows for rapid, timely interventions. There is a thin layer of case management catching the problem, addressing it, and handing it off to the healthcare delivery system the next business day. If someone is showing signs of anxiety, IBIS might walk him or her through taking deep breaths – whatever the protocol is for that individual. As we detect problems, we send a text message alert to the case management team, who then provides a proper hand off to the individual’s larger care team. The Warbler device tracks movement within the house, looking for deviation from normal patterns. This technology has the robust capability to manage all of a patient’s medical/clinical records as well. Having an individual tell his or her story over and over again is painful – the system allows the right documents to be shared, with the right caregiver, and at the right time to avoid this. The Care Station is one place where everything is organized to help with caring. It also provides trending data over time. The data will show how well an individual can self-manage and what activities they need assistance with. The essence of this is all about population health management. We want to understand how chronically ill populations manage themselves, where there are gaps in care, and where systematic interventions exist to lift the health of the population.

**Discussion:** It was asked who is on the primary care team, which has access to this data.

**Piali:** The primary care team includes a clinician, a nurse, and someone called a Care Navigator (social worker). The Care Navigator and the nurse are provided by Senscio. They are designed to augment the existing care team, provide 24/7 coverage, and a proper handoff. The team is who you want it to be. The Senscio team will notify the proper providers who are already in the individual’s system of care. They act as a first line of defense.

There was discussion about the possibility that this system and data could be abused, in that it may interfere with the rights of a person – a “big brother is watching” feeling. Some felt that this should be more of a last resort. The group also wondered how consent works and what happens when someone is under guardianship.

**Piali:** Consent is provided by the individual. What is structured is up to the person. Some just want structure around medications and vital signs. The technology allows for everything to be structured, but you do not need to monitor everything. For instance, bathroom usage may not need to be monitored. Some people very much object to monitoring bathroom usage because it is intrusive and uncomfortable. If there is confidence the person is doing everything and they don’t have major concerns than the individual would likely need less observation. The level of observation depends on needs. The issue of guardianship hasn’t come up for us yet. It was stated that it would depend upon each state’s laws governing what a guardian can and cannot consent to on behalf of an individual.

**Cullen:** One of the things in my mind was the idea of cameras watching someone’s every move. I understand that there are no cameras at all. A device is worn around the neck and data and algorithms are used to determine patterns and anomalies to the patterns.

**Piali:** That’s correct. The data is all self-reported. Many elderly individuals forget if they’ve eaten. There is a lot of anxiety around medications as well. Structure, and reminders, of these activities matters to some people.

**Mike:** The beauty of the system is that it is built around the artificial intelligence. You don’t have to sit in front of a computer screen to look at and analyze data. You decide what you want to know – if someone is missing critical meds, not showering two days in a row – that’s what you tell the system, and the system sends an alert when that occurs.

Electronic records between Maine Medical Center and Mercy do not communicate with each other. Additionally, Maine has issues with internet connectivity. It was asked how both of these would affect the technology.

**Piali:** We have some homes where people are using broadband or a 3G network. The broadband infrastructure in the whole state needs to improve. Regarding electronic medical records (EMR), we are poised to be able to integrate data from EMR systems. We have found that often times the data in the EMR system isn’t correct, or it doesn’t paint the whole picture. We have found that they are actually using our data because it is more reliable and complete. We’re ready to interface wherever we need to.

It was asked when the IBIS will be available and how much it costs.

**Piali:** The technology is available now and we can get it to anyone who is interested; we would just need to work through the details. We have six customers we’re actively deploying through. We have two deployments in Maine and we’re looking for more. The cost is likely not covered by public insurance (MaineCare). The monthly cost is between $95 and $195, hardware included. Cost is determined by what level of care coordination you want. In South Dakota, this is being deployed with the help of the parent community connection (a group similar to the Maine Coalition for Housing and Quality Services). They have been able to work with support providers, and support providers are getting it authorized through the HCBS (Home and Community Based Services) waiver.

**Cullen:** Thank you both very much. This was a wonderful, informative presentation!

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

**Featured speaker: Mel Clarrage, Chair, and Mike McClellan, Executive Director, State Independent Living Council (SILC)** [**mainesilc.org**](http://mainesilc.org/)**. Topic: Three Year State Plan for Independent Living**

**Mel Clarrage:** The State Independent Living Council (SILC) is very similar to the DDC ([Maine Developmental Disabilities Council](http://www.maineddc.org/)), but we are cross-disability. We look at all individuals, regardless of the type of disability and age, regarding independent living. SILC is federally mandated through the Rehabilitation Act of 1973. SILC was very vibrant in Maine in the 1980s. Activity died down for a while, but SILC is more active and visible now. We’re in the midst of developing the next three year state plan, which drives priorities for independent living in Maine. The last time around, we held public forums and conducted surveys. We received input from far fewer than 1000 individuals, falling significantly short of our goal. We are looking to get feedback from 1000+ individuals this year. Traditionally plans are driven by providers and a small circle of people with disabilities who work within the system. Twenty percent of the population in Maine has disabilities; we need to do a better job determining their unmet needs.

**Mike McClellan:** We are currently turning rocks over and making noise in Augusta in an attempt to benefit people. I’ve found a lot of people in Augusta don’t understand what independent living is. A lot of times the focus is on jobs. We’re trying to spread the message that jobs are really important, but they’re part of a healthy lifestyle which includes independent living. We have been working on the survey from three years ago. We put a good group of people together and made changes to the survey, which includes transition. We are within days of having the final draft. We’re gearing up to get into northern and western Maine, places that didn’t have access to the survey last time. The survey will be online. We will hold community events, and seek out groups like this to complete surveys – any place where people gather. We’re trying to be as creative as we can. I ask that you all keep us in mind in your world and share this survey.

**Cullen:** We would be happy to post the survey and any other materials on the Maine Parent Coalition’s website.

**Mel:** One of the key things about SILC is self-empowerment. We want to hear from people with disabilities. We want them to direct how they live their lives to the fullest extent possible.

**Mike:** In addition to my role with SILC, I’m also a State Representative. There was an unfortunate situation last session were two very important issues were pitted against each other – the waitlists and asylum seekers. Advocacy for asylum seekers was very effective – every day there was a picture of someone and you wanted to help that person. People with special needs and disabilities don’t have names and faces in Augusta. My goal is to change that next session. I invite you to connect with me, and share stories with me. I want the powers in Augusta to know these are real people.

**Discussion:** It was stated that libraries are big gathering places and could be an ideal place to reach people for the survey. It was suggested to integrate the community and public forums with ones that are already occurring, as there is always something going on concurrently.

**Mel:** We are trying to broaden the scope of what we’re doing and integrate the work from the MDSOAB ([Maine Developmental Services Oversight and Advisory Board](http://www.mainedsoab.org/)), the DDC, and other groups. We really have to coordinate that more effectively to ensure that the needs of people with disabilities are being addressed.

**Cullen:** Thank you both very much for presenting!

**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:** As of 9/30/15, there are 1185 people on the Section 21 waiting list: Priority 1 = 0; Priority 2 = 430; Priority 3 = 755. For Section 29, applications have been on hold since 7/1/15 and no waiting list has begun; I am currently beginning to make Section 29 offers in order of the date the application was received, 1:1 in accordance with the recent offers that have been declined. (Sent after the meeting).

**Brian:** We are moving forward with the SIS ([Supporting Individual Success initiative, Supports Intensity Scale tool](http://www.maine.gov/dhhs/oads/trainings-resources/initiatives/sis.html)). We have been granted an extension and it will be launching tentatively on 1/1/16; with plans set for 7/1/16. Due to the fact that the behavioral regulation is currently open for public comment I cannot comment on it at this time. I know that the Department wants feedback. Comments are due at 5:00 pm today.

**Staci**: Disability Rights Maine ([DRM](http://www.drme.org/)) submitted 14 pages of comments regarding the behavioral regulations. ([Click here for DRM’s letter](http://www.maineparentcoalition.org/october-2015-presentation.html).) Our main concerns were how confusing the behavioral regulations are, and that they include inconsistencies and were difficult to understand. We requested clarity regarding the safety device provision – what exactly is a safety device? With the ambiguity in how it is written it seems to suggest that some things would not go before the committee: Behavioral intervention versus an intervention to restrict unintended movement. We are asking for clarity regarding whether it is only used for unintended movement. Cullen shared DRM’s letter with the group. If organizations or individuals are interested in signing on to the letter they are more than welcome to. We are unable to make changes or amendments to the letter, however.

**Cullen:** The folks who read DRM’s comments thought they were well conceived but had some comments.

**Discussion:** It was stated that DRM did a great job and most of the recommendations were excellent. Some people expressed disagreement or confusion with some of DRM’s comments. The group discussed floor restraints, what is considered a restraint, careful thought before using restraints, chemical restraints, de-escalating versus using restraints, and standardized versus non-standardized restraints (how non-standardized restraints can be beneficial in certain circumstances). It was stated that it would have been beneficial for the department to solicit suggestions regarding the language used in the regulations. The group thought that they were extremely hard to comprehend, with some saying they were altogether unreadable. Due to the extreme difficulty in reading the language it was challenging to get to the meaning.

**Cullen:** Anyone can individually send comments regarding this. The comment period ends at 5pm today. If folks individually want to sign on to the DRM letter what would they need to do?

**Staci:** Email me at sconverse@drcme.org before 4pm today. I want to encourage people to submit comments, even if it is as basic as “the regulations were hard to read and there was not enough time to respond during the comment period.” Please send them.

**Cullen:** Does that summarize how a lot of people feel? Would that be a message the Coalition would like to send?

A motion was made, and seconded, for the Maine Coalition for Housing and Quality Services to send feedback stating “the regulations were hard to read and there was not enough time to respond during the comment period.” All were in favor; representative from DHHS abstained. The motion passed. Cullen will submit this feedback on behalf of the Coalition today, prior to the 5pm deadline.

**Legislative Updates:**

**Representative Peter Stuckey:** The Health and Human ServicesCommittee is trying to figure out how to provide the oversight expected, without having access to the information needed. Right now we are working on the [Fund for Healthy Maine](http://www.mainepublichealth.org/advocacy-and-policy/priorities/fund-for-healthy-maine/), among other things. We’re trying to do it by ourselves. The Department hasn’t been able to be present. I continue to be concerned about competing interests for limited resources. It’s important, particularly as the waitlist issue starts to play out, that we really understand how it’s going and we get information at the legislative level from all involved – the Department, provider, and most importantly the consumer’s perspective. I worry that the venue for that is going to be hard to find. I encourage this group and others to anticipate what your homework is and figure out how to get information to us, if and when we get to a place where we can take a look. I’m worried we put a whole lot of money into the budget and I want to make sure it gets spent the way it was intended. Something some of us are worried about, as we make the transition that everyone philosophically agrees with, is that the changes play out in a way that’s actually improving the lives of folks in need of the services, and expands the population that has access to it. You can’t expand the population at the expense of making sure people get what they need, no more no less, when they need it. It’s hard when you’re making changes like this. It is unsettling that there isn’t more transparency about that process and transparency about continuous quality improvement at every step of the way. People, this group included, have worked hard to get a well-designed system on paper; it would be a shame to not be able to see it through to its implementation in a way that’s worthy of the plan and the quality of the effort that went into making it. Vigilance and continued presence at any place where you find an opportunity to contribute is critical.

Do other committee members share your concerns?

**Peter:** I don’t think I’m the only one on the committee that shares the concern with the same intensity. Though, others on the committee appear to be content to let the Department handle the situation, just assuming it’s going well. It’s hard when as a whole committee we don’t hear from the Department. If I don’t know anything I’m left wondering, and that’s where we are as a committee and as a Legislature. I don’t see a path to the end clearly mapped out and that’s why I say vigilance and continuing to cultivate a shared community response is really important.

It was asked if the committee addressed the proposed cut to SSDI, scheduled to take effect as of November 2016.

The committee has not addressed this at all. On the federal level, there has been a bipartisan effort made to put in a bill so this does not happen.

**Cullen:** Thank you for the call to be vigilant. I think we will certainly do that. Thank you for being here! On the federal level, the government is operating under a continuing resolution (CR) that runs through 12/11/2015. The Challenge between now and then will be raising the debt ceiling. There is hope, with about a 50/50 chance of success, to get an Omnibus bill passed before the end of the year and fully resolve sequestration. If this doesn’t happen we will face the full effects of sequestration. This would affect Section 8 and other housing programs. Our delegation is well informed about this.

**Children’s’ Services**

**Rachel:**  We are now fully staffed in all three regions. We are currently looking at resource development.

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

**Stacy Converse:** We have two new advocates, one in the Lewiston Office and one in the Augusta office.

**Other Business, Announcements:**

**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.

**Cullen:** At our next meeting on **November 9, 2015,** 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).***