January 8, 2018

Minutes

Present: Nell Brimmer, Mary Chris Semrow, Michael Chapman, Lisa Cohn, Linda Lee, Lisa Brayall, Kim Humphrey, Jennifer Putnam, David Cowing, Lydia Dawson, Joanna Bulger, Margaret Cardoza, Nonny Soifer, Skip MacGowan, Cullen Ryan, and Vickey Rand. Via Zoom – Bangor (UCPofME): Elizabeth Whitmore. Sanford (Waban): Brenda Smith. Winthrop (Autism Society of Maine): Cathy Dionne and Ann. Auburn (John F. Murphy Homes): Ann Bentley. Brunswick (Independence Association): Ray Nagel and Colleen Gilliam. Farmington (LEAP): Kristin McPherson and Joyce Daggett. Misc. sites: Stacy Lamontagne and Romy Spitz.

Cullen Ryan introduced himself and welcomed the group. Participants introduced themselves. Minutes from the last meeting were accepted.

*Thank you to Senscio Systems, who has very generously covered the cost of lunch for our 2018 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)*.*

**Cullen:** Before we begin, I wanted to see if we have anyone here from DHHS today, either OADS or OCFS. (There was no one from DHHS in attendance in Portland or the remotes sites). I’ve tried emailing and calling staff at OADS, with no luck. We’ll keep trying to invite them to be at this table. If anyone arrives from OADS or OCFS at the remote sites please let us know, because we have them on the agenda in hopes of hearing long-awaited updates.

**Featured speaker: Linda Lee, Co-founder, Jonno’s Place.** [**Jonnosplace.org**](http://Jonnosplace.org) **Topic: Jonno's Place: a new perspective on disabilities. Examining what our community and the community at large needs, and where and how these communities can coalesce.**

**Cullen:** Linda Lee is here today to present on Jonno’s Place. It sounds like they are intentionally creating a place in which people can be included as part of the community; I’m excited to learn more. Welcome, Linda, and thank you for being here!

**Linda Lee:** Jonno’s Place started two years ago, named after a young man named Jonno. Jonno was diagnosed with Asperger’s and was fairly high-functioning – he had a driver’s license, was fully verbal, brilliant with electronics – but like so many, he lacked social and emotional skills. He lived at home with his parents and had a few friends. One day he wandered away from the home; he was found dead the next morning. This was the catalyst for the creation of Belfast’s Wandering Database. We wanted to create a support system and environment for people like Jonno, in which people can live rich, productive lives. Jonno’s Place offers a new perspective on disabilities. We consider: What does our community and the community at large need? Where and how can these communities coalesce/come together?

**Begin Presentation (**[**Click here to view the presentation**](http://www.maineparentcoalition.org/january-2018-presentation.html)**)**

**Linda:** Before I became a parent I was an ER nurse, and never once did I, or my colleagues, receive information on Autism and how best to care for someone with that diagnosis. I knew nothing. My son was diagnosed with Autism around age two, through early intervention. He was self-injurious, and aggressive towards others. In an attempt to educate myself I spoke with other parents. One parent told me about changing things in his environment. Milk and gluten were removed from his diet, and he showed improvements. After other changes to his environment he began to develop more normally. He had been in constant pain before his environment was altered.

One of the challenges with Autism is that often times kids have immense, incredible talents and splinter skills, but at the same time they’re functioning at less than three years old in terms of adaptive functioning skills, and often don’t like social situations and can’t cope with them. This presents a huge dilemma and doesn’t just affect the person with the diagnosis, it affects their families, and has a profound impact on the entire community.

As parents, we know it’s a total crisis. There are waiting lists for services. I was told by my son’s case manager that I’ll be dead before he receives services. What do we as parents do? What happens to our children when we die?

Through Jonno’s Place, we’re trying to create an environment, a community, where people can come together, are treated equally, and where no one is served or serves. This is the [Camphill difference](http://www.camphill.org/about-camphill/). This is a model in which traditional “staff” are instead, more often than not, volunteers. These volunteers want to be there, to create and share a life there. This is our dream for Jonno’s Place.

([Click here for James’ story, and becoming a Junior Firefighter referenced in the presentation.](https://jonnosplace.org/?p=566)) This is just one story – but change happens through numerous individual stories just like James’. I’m excited about this idea of bringing our communities together. If we can do that, people will be supported and won’t need as much funding for services – funding that is extremely hard to access currently. People would be part of the community. We’re just a group of people trying to make a difference, so that our children are well cared for.

**Discussion:**

-It was asked if waiver funding is part of the project.

**Linda:**  We don’t know for sure yet. Plus, the waiting list for Section 21 is so long – people could be waiting for fourteen years to receive services. We’re writing grants and doing everything we can to secure the necessary funding. We’re going ahead with this as if we have the money to do it; things keep falling into place.

-It was asked if this housing model would work for everyone.

**Linda:** I think for sure, yes. Why would it not? Everyone may not behave this way, but we’re all equal. Everyone has something of value to contribute to the community, from which everyone benefits.

-It was asked where is the nearest Camphill.

**Linda:** There’s one in Vermont, [*Heartbeet Lifesharing*](http://heartbeet.org/).

-A member of the group stated that he attended an open house at the Camphill in Vermont this past October. He stated that he came away from the experience feeling very hopeful. At the same time he wondered if this is a particular way of life for the people volunteering there as well. The volunteers were not looking to “serve” someone, it was more of a reciprocal agreement; that was refreshing. It was asked how Jonno’s Place is being funded. In Vermont, there isn’t a waiting list for services. He stated that he’s very interested in this type of model, and the appetite seems to exist in the community as well.

**Linda:** What happens to these kids? My boy is 19 now; he’s a big, full-grown man. However, he behaves in a manner that is more like a two year-old. What’s going to happen to our kids? What an opportunity we have here, to create a legacy that will carry on. Camphills have been in existence for decades. This is a sustainable model. When designing Jonno’s Place, we didn’t want to replicate the Camphill in Vermont, for various reasons, but primarily because we wanted it to be available to anyone who has nothing financially, because we all bring things to the table.

-It was asked how Camphill would fit into Jonno’s place; what role they would play.

**Linda:** You must be a Camphill person to start a Camphill. We’ve worked with them from the start; we created our bylaws to coincide with theirs. We’re working closely with them. Our dream is that the Camphill people will come once we get things set up. Then, Jonno’s Place could become an affiliate, and eventually a member, with the hope of eventually turning it over the them.

-It was asked if individual choice is included in this model, where the individuals get to choose their housing arrangements and activities.

**Linda:**  Totally. That’s what the whole [Home and Community-Based Services (HCBS) Final Rule](https://www.medicaid.gov/medicaid/hcbs/guidance/index.html) is all about.

-It was stated that respite services are sorely lacking. It was asked if they had considered working respite services into the model.

**Linda:** That’s come up, and is something that I could see become part of this community as it evolves – to provide respite for people who may not live there full-time.

-It was asked if they are worried about the remoteness of the location, which was described as being across the bridge in Belfast, right off Route 1, but on the Searsport side. It was asked how they planned to integrate the Jonno’s Place community with downtown Belfast.

**Linda:** The [transportation provider in Waldo County](https://waldocap.org/?page_id=71) will come pick people up wherever they want. The plan down the line to have a program in town. We don’t see the location as an obstacle, as we do have transportation. Also, the Fireside Inn is right beside us, if people wanted to work there.

-It was asked if they had considered having people without disabilities live in the same area, on the same site.

**Linda:** Yes, if they believe in the same philosophy. We’re all equally doing this. Our dream is that people of all abilities will be involved, but they must have the same philosophy.

-It was asked if there are additional requirements. It was mentioned that Linda referenced [Rudolf Steiner](https://en.wikipedia.org/wiki/Rudolf_Steiner) and [Waldorf schools](https://waldorfeducation.org/waldorf_education) in her presentation.

**Lisa, Jonno’s Place Board Member:** People would be part of the community and expected to participate. They need to want to be part of the community or it wouldn’t work.

-It was stated that starting a community within an already vibrant and strong community such as Belfast sounds appealing, but there is the desire to hear more about integration into the larger community.

**Lisa:** That’s why we want to be in Belfast. We’re already having these discussions with the community. That’s what we want, for people to be fully included as part of the community. We don’t want to reinvent the wheel, we want to use what’s already in town.

**Linda:** This is stage one, and there will be a stage two, and probably a stage three down the line. Belfast is in dire need of affordable housing. This is one of the reasons why Belfast has such a shortage of workers – there’s little to no rental housing.

-It was asked if the tiny houses are on trailers or foundations.

**Linda:**  You can’t have a tiny home as a permanent residence in Belfast. We’re working closely with the city of Belfast. The State of Maine is in the process of changing the minimum square footage required for a permanent dwelling as we speak, so we don’t know where that’s going to fall.

-It was stated that the Camphill in Vermont has volunteers who sign up for a minimum of one year, to a maximum of five years. This commitment would likely be important to making budgets work. It was asked if Jonno’s Place would have paid staff, or if it would solely have volunteers.

**Linda:** Historically, Camphills have been completely volunteer-driven. This is also evolving to include paid staff. [Camphill Hudson](http://www.camphillhudson.org/) is the first Camphill that has gone to an all employee-based model. If you want to attract volunteers, it’s helpful to have incentives; having an attractive town such as Belfast acts as an incentive. We applied to the [Hutchinson Center](https://hutchinsoncenter.umaine.edu/) for scholarships as another way to attract people. It’s very much volunteer-driven. Volunteers sign up for a minimum of one year, of which almost the entire time they’re “on.” There is one day off per week. They don’t “work” schedules, they’re on all the time.

-It was asked if this model would work well in extremely rural Maine.

**Linda:** Camphills like to be within a certain distance of Waldorf schools.

**Lisa:** Jonno’s Place has changed and evolved many times since its inception two years ago.

-It was stated that this model sounds phenomenal. It was stated that too often we forget that people with ID/DD want to have the same, wide variety of housing options that others have.

**Linda:** People in Maine are being brought to emergency departments and then being discharged from the agency providing services. Services are essential, but accessing and retaining them is very difficult. My son wants his own space, but he needs a lot of support to live in his own space safely. This model addresses both the housing and the supports needed to live and thrive in the housing. We’re excited and we’d love for you all to join us.

**Cullen:** Thank you, Linda, for this informative presentation. It was fantastic and gave us a lot to think about. Well done!

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

**DHHS, Office of Aging and Disability Services (**[**OADS**](https://www1.maine.gov/dhhs/oads/)**) & Office of Child and Family Services (**[**OCFS**](http://www.maine.gov/dhhs/ocfs/)**):**

**Cullen:** It doesn’t appear anyone from DHHS has arrived at any of the remote sites. (The remote sites confirmed this). Since we do not have representation from the Department, does anyone have any updates from either OADS or OCFS?

**Lydia Dawson:**  The Department released notice of agency rulemaking for rules that pertain to abuse, neglect, and exploitation. It appears that the Department is looking to make a large shift in APS (Adult Protective Services). The Department decided to bifurcate the public hearings for the APS and the Critical Incident Systems regulations into two separate dates. Both still have a written comment period, with comments due on Monday, January 22, 2018 (they can be emailed to Erin Salvo at [Erin.Salvo@maine.gov](mailto:Erin.Salvo@maine.gov)). If you can make it to both public hearings, great, but if you can’t, MACSP is trying to have great attendance at the APS public hearing, tomorrow. ([Click here for more information.](http://www.maineparentcoalition.org/january-2018-presentation.html))

* The Adult Protective Services System Public Hearing is on Tuesday, January 9, 2018 at 9am at DHHS 41 Anthony Ave in Augusta.
* The Critical Incident System Public Hearing is on Wednesday, January 10, 2018 at 9am at DHHS at 41 Anthony Ave in Augusta.

The Department is proposing to repeal the current reporting and APS regulations, and replace them with two separate sets of regulations – APS System regulations and Critical Incident System regulations. With these changes, it appears there will no longer be “reportable events.” After examining the proposed rule changes, I noted some of the more important changes. ([Click here for Lydia’s talking points on the APS and Critical Incident System regulations.](http://www.maineparentcoalition.org/aps-and-cis-regulations-info.html)) We have APS statutes that exist to govern APS and give baselines, the bare minimum expectations. The regulations are supposed to better flesh out APS procedures. The regulations we have in in APS Act, came out of the Community Consent Decree. The proposed APS rule changes would be eliminating those and going back to the bare minimum. The APS Act says that the Department shall investigate any allegations of abuse, neglect, or exploitation. The proposed regulations propose a series of caveats when the Department would not be required to investigate, some of which are incredibly broad and concerning.

The Critical Incident System regulations appear to cover everything else. The big takeaway is the Critical Incident System, appears to be a system in which the responsibility falls on providers. Providers would make the report, provide an internal review, and upload that information into the system. Currently, the Department reviews this information and makes a determination regarding where it should go, where it needs to be investigated, what oversight is needed, if it rises to the level of APS involvement, if there are licensing concerns, and so on. The proposed Critical Incident System regulations would create a system where providers are policing providers; this is not a relationship that’s conducive to having appropriate system reform. What appears even more concerning is that the Department said in its response to the [OIG report](http://www.maineparentcoalition.org/oig-report-information-august-2017.html), that they will investigate every death individually, and review every critical incident by internal review. These regulations are sending a message to providers that they need to police themselves and let the Department know if anything is wrong. This is not conducive to providing services well.

**Cullen:** Thank you for this information, Lydia. That sounds alarming. We will want to watch this to ensure the system is prioritizing safety for our sons and daughters.

**Lydia:** Additionally, comments for the Department’s [Section 29 Waiver Amendment Application](http://www.maine.gov/dhhs/oms/rules/Section29WaiverAmendment.shtml) to CMS ([Centers for Medicaid and Medicare Services](http://www.cms.gov)) are due tomorrow. The application is approximately 200 pages. It appears to be a recycled document with some updates. It appears the Department failed to remove old, outdated information from the application, as it still references the SIS, among other things, and references data from 2014.

-It was stated that NPR is currently running a series on people with disabilities experiencing sexual abuse. ([*Click here for the NPR series “abused and betrayed: people with intellectual disabilities and an epidemic of sexual assault.”*](https://www.npr.org/series/575502633/abused-and-betrayed) Please note that NPR includes a disclaimer: This report includes graphic and disturbing descriptions of assault.)

**Lydia:** People with ID/DD are victims of sexual assault at a rate that is five-times the national average.

**State Legislature Update**

**Lydia Dawson – The Maine Association for Community Service Providers (**[**MACSP**](http://meacsp.org/)**):** We’re hoping to address the second year of funding for DSP rate increases, that was not included in the biennial budget as part of LD 967 during the last legislative session. We hope it will put us back to the 2007 rates, plus some adjustment for inflation. As minimum wage increases it becomes even more difficult to incentivize DSPs; providers are having a very difficult time hiring and retaining staff due to the low wages paid.

**Jennifer Putnam:** The question remains whether this will be stand alone, or folded into the budget. We will keep everyone posted. In the meantime, if folks can reach out to their local legislators, especially if they’re on the Appropriations Committee, it would be helpful. Legislators want to hear how the high turnover rate for DSPs has affected the care provided.

**Cullen:** Historically, one of the issues with the Legislature is that legislators get very busy, and as they get busy they’re harder to reach. Now is an ideal time to reach out to your legislators before they are inundated with numerous public hearings, work sessions, and so on.

**Lydia:** We’re also hoping the Legislature will accept our bill to increase the Section 28 rate. Burns and Associates did a rate study, which proposed cuts to various services. The Legislature approved a moratorium on those cuts, however Burns proposed a rate increase for Section 28, which has yet to occur.

The Department is proposing to move Child Development Services for three to five year-olds from the Department of Education (DOE) to the public school systems. Numerous questions remain unanswered about how it would work, and whether schools have the capacity to take this on, especially without additional funding. We will likely see legislation regarding this soon.

**Jennifer**: These are schools that lack capacity currently, which will have immense difficulty taking this on. Rural areas will also face unique challenges. In rural areas you might have a three year-old on a bus for an hour with a ten year-old.

**Lydia:** Maine Parent Federation has expressed that the lack of choice is a major concern for parents. Parents would lose the ability to decide who provides services for their children, and what services are provided. Families would be limited to their local school districts. There is also a more general concern that this would constitute a form of discrimination – having schools provide programs for three to five year-old children with ID/DD, while not providing this to three to five year-olds without an ID/DD diagnosis, would single out kids with ID/DD in the school.

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

**Nell Brimmer:** The DD Advisory Council is restarting Partners for Positive Change. Its first meeting is tomorrow.

**Federal Update:**

**Cullen:** We received a reply from Senator Collins, regarding our letter to her on the tax bill. Her letter suggests she’s confident we won’t see the harmful effects we predicted due to the tax legislation. I hope she is right. However, I’m still hearing from other experts that this is not the case. Due to PAYGO requirements of the Senate, we would see sequestration cuts to all Non-Defense Discretionary (NDD) programs, including cuts to HUD programs like Section 8 and the HUD 811 program, on which people with disabilities and other vulnerable populations depend. Then, part of Congress wants to take a look at Welfare reform, so entitlement programs would be next on the chopping block, including Medicaid, Medicare, and Social Security. But other parts want only bipartisan approaches to changes to entitlement programs, so we will see. People with ID/DD rely on housing, which is funded through HUD, and services, which comes from Medicaid. In Maine, Medicaid extends into Special Education funding as well. The good news is that Senate republicans think there ought to be a bipartisan approach around any welfare reform. We’ll be watching this closely over the coming months. Additionally, the federal government is currently operating under a Continuing Resolution (CR), which funds the government through January 19th. If Congress doesn’t approve another CR or pass an omnibus spending package, the government would shut down. At this point it appears another short-term CR is more likely than a 2018 Omnibus bill.

**Housing Update:**

**Cullen:** We haven’t heard any updates from the Department about the HUD Section 811 program, which is supposed to provide Section 8 vouchers to people receiving waiver services. I hope to have more information on this for the next meeting.

-It was stated that with the expansion of Section 29, people can use Section 29 for shared living. It was stated that it would appear that if someone opted to use Section 29 for shared living, there would be no funding remaining to access day programming.

**Lydia:** Section 29 has a cap on the money you can put towards all of them. If someone wishes to access a 24/7 shared living model for the entire year, they will reach the Section 29 cap, with no remaining funding for any other services included in the cap (work supports have been removed from the Section 29 cap). The Department’s responses to written comments on the Section 29 rule changes have come out. The Department’s response to the lack of community integration due to this is that people get plenty of community integration in shared living, they don’t have to have access day programming to do so.

**Jennifer:** We have multiple scenarios playing out currently including: People splitting the care of an individual; people providing shared living for their family member on the weekend, and someone else during the week to leave funding for other services; and people utilizing community supports full time. The expansion of and changes to Section 29 offers a wide range of flexibility that wasn’t there previously.

The next meeting will be on **February 12, 2018**

**Featured Speaker & 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).***