December 11, 2017

Minutes

Present: Jeff Levy, Jerry Silbert, Laurie Raymond, Julie Brennan, Erin Rowan, Rachel Dyer, Kim Humphrey, Bonita Pothier, Jennifer Putnam, Ed and Suellen Doggett, Skip MacGowan, Patrick Moore, Nonny Soifer, Michael Chapman, Lauren Wille, Janna Bulger, Deborah Freedman, Margaret Cardoza, Shannon Cantara, Tiffany Dupelessis, Shylah Clark, Cheri Cluff, Peter Stuckey, Leslie Mason, David Cowing, Cullen Ryan, and Vickey Rand. Via Zoom – Bangor (UCPofME): Elizabeth Whitmore. Winthrop (Autism Society of Maine): Cathy Dionne and Ann. Sanford (Waban): Brenda Smith. Auburn (John F. Murphy Homes): Ann Bentley. Brunswick (Independence Association): Ray Nagel and Colleen Gilliam. Camden (Coastal Opportunities): Hillary Steinau. Farmington (LEAP): Kristin McPherson, Joyce Daggett, and Darryl Wood. Misc. sites: Stacy Lamontagne and Romy Spitz (with interpreters).

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 2017 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: Leslie Mason. Topic: Part four of the history of the system of care for people with intellectual/developmental disabilities, including Pineland. An individual who lived at Pineland will share his life experiences with the group. This is part four of a multi-part series.**

*(*[*Click here for an audio recording of the meeting, including the featured speaker/presentation*](http://www.maineparentcoalition.org/december-2017-presentation.html)*)*

**Cullen:** We were supposed to have another speaker today, but she has fallen ill. We wish Vanessa a quick recovery and hope she can join us at a future meeting. I want to thank Margaret for doing a lot of behind the scenes work to tee up today’s presentation. Today we’re going to hear from Leslie Mason. Leslie is willing to speak to you today about his past experiences at Pineland, and about his life now. After he speaks, he is willing to answer some questions from the group. If some questions seem too private for him, he may choose not to answer them, and that’s absolutely fine with us. Please save your questions for after his presentation. Welcome, Leslie, and thank you for being here!

**Leslie Mason:** I was born in 1945, and lived with my mom, dad, bother, and sister. My dad worked in the blueberry fields. Eventually my step-mom came along; she said I made her feel uncomfortable. In 1958, at 13 years old, I was sent to Pineland. One time I was watching TV, and someone broke a bottle over my head. I was at Pineland for 21 years; I was discharged in 1979. I used to be a member of the CAB (Consumer Advisory Board). I have been married for 25 years. Now, I live in my own house with my wife. We’ve lived there on our own for nine years. I have a brand new car and work at two jobs in Biddeford. I am very happy. I tell my story to remember the past, so people don’t send kids like that away anymore. *(Large round of applause).*

**Discussion:**

-It was stated it took a lot of courage to present today. There is no one better to speak to the truth of what occurred at Pineland then someone who experienced it first-hand.

-It was asked how Leslie met his wife.

**Leslie:** I met her in Portland, years ago.

-It was asked what the one thing is that meant the most to him, that helped him, over the years.

**Leslie:** Getting out of Pineland.

-It was stated that it must have taken a lot of strength and courage to get through each day at Pineland. It was asked if while he was there he thought he’d ever be able to leave, or if it felt like he was going to be at Pineland for the rest of his life.

**Leslie:** I thought I was going to stay there for the rest of my life.

-It was asked what that felt like.

**Leslie:** Not good.

-It was asked if Leslie made friends at Pineland who remained in his life after leaving.

**Leslie:** I made a few friends; I don’t really see them.

-It was asked what he does for work in Biddeford.

**Leslie:** I work at Hannaford as a bagger; I’ve been there for two years now. I also work at Tom’s of Maine in Sanford.

-It was asked what type of jobs and community involvement Leslie has had over the years.

**Leslie:** Years ago my wife and I lived in Portland and I used to work at the Portland Country Club and at Bugaboo Creek. I’ve worked at quite a few places. I also volunteer at City Theatre in Biddeford as an usher.

-It was asked where Leslie lived after he left Pineland and how that environment differed.

**Leslie:** I lived in a group home in Portland. It was different.

-It was asked if Leslie saw his family while he was at Pineland.

**Leslie:** No, I didn’t see them.

**Cullen:** You said it was different being in a group home versus living at Pineland. Can you describe the differences more?

**Leslie:** It was better. I didn’t have to worry about bars being on the windows.

-It was stated that group homes were different in size, but some things didn’t change compared with the conditions and treatment at Pineland. However, it was still a vast improvement.

-It was asked if Leslie could describe some of the things he could do when he lived in the group home that he was unable to at Pineland.

**Leslie:** I could go into the community more.

-It was asked if he had any schooling or training while he was at Pineland.

**Leslie:** I went to school there, and I worked on the farms. I also learned to drive there; they had Driver’s Ed. They held on to the license though.

**Cullen:** Do you receive support now where you live, or do you do it all by yourself?

**Leslie:** People help us out – go on walks with us, help with cleaning the house. My wife does the cooking.

**Cullen:** How does that make a difference for you? That’s one of the things we try to work on here – how to make the world better. We are working to ensure people have the support they need to be successful and included as part of their community. Here you are, living your own life, working independently, and you have people around you giving you support. This is exactly what we hope everyone has the opportunity to do – to live a full and meaningful life. Can you describe the difference the support makes for you?

**Leslie:** It makes all the difference.

**Cullen:** If you didn’t have support, how would your life be?

**Leslie:** Not good.

**Cullen:** We think about ways in which we can make the world better – far better than Pineland – to have a service system that treats people with dignity and respect, and provides the services needed to be successful in the community. At Pineland, it seemed people were stuck in one place, and didn’t have choices or freedom. Does it make sense to you to have people work independently and have the support they need around them to do so?

**Les:** Yes it does.

-It was asked how Leslie got his current jobs.

**Leslie:** I went out on my own and found them; sometimes people helped me with that.

-It was noted by one of his support staff that Leslie got his job at Hannaford all by himself. He works with a Job Coach for his job at Tom’s of Maine.

-Previously, Leslie mentioned that he didn’t want what happened to him to happen to anyone else, ever again. It was asked what he hoped for children today with intellectual/developmental disabilities.

**Leslie:** For them to be happy.

**Cullen:**  Well, I don’t know you very well Leslie, but you strike me as a happy person. I want to thank you for having the courage to come here today, for letting us ask some questions, and to have a glimpse into your life. Thank you for telling your story!

**Leslie:** Thank you for having me.

**End of presentation.** *(Large round of applause)*

**Featured speaker: Deborah Freedman. Topic: Deborah will tell her story of learning about her sister, who was sent to Willowbrook State School in Staten Island, New York.**

**Deborah Freedman:** This past spring/fall was a very dramatic ending, or rather a beginning, to my life. I’m 70 years old, and I always believed I had a sister, but no one would ever confirm this feeling. I was born in 1947; my sister was born in 1948, and disappeared sometime during that first year. In my child mind, I said: What did I do? Did I cause this? Did I kill her? This has stayed with me for all these years. I believe that her name was Susan. That belief has gone on all my life.

In 2013, I wrote a book of fairytales that depicted looking for her and never finding her. This spring my friend was on [ancestry.com](https://www.ancestry.com/), and I asked her to look up Susan Blankenstein, whom I believed was my sister. She searched for Susan, and her name did in fact pop up. I discovered that she was buried at Mount Richmond Cemetery on Staten Island, after arriving at some school called Willowbrook ([Willowbrook State School](https://en.wikipedia.org/wiki/Willowbrook_State_School)). She lived until the age of four. I researched Willowbrook, and my heart broke at what I found. My parents must have brought her there. In this moment, I knew I was going to Staten Island.

That fall, my daughter who lives in California was going to a wedding in Manhattan; I asked her to come with me to Staten Island to visit the cemetery while she was in the area. The cemetery is run by the [Hebrew Free Burial Association](https://www.hebrewfreeburial.org/), which provides free burial plots to Jewish people considered to be “indigent.” When we arrived at the cemetery a man stepped out of a car, he introduced himself as the Rabbi. I knew the section of the cemetery in which my sister was buried, so I asked him where it could be found. His response was, “oh, the children!” All the Jewish children at Willowbrook were buried in a mass plot. Margaret warned me that my sister’s grave might be marked with a number, rather than her name. The Rabbi wasn’t sure if we’d be able to locate the plot, but he directed me where to go and said he’d meet me there. My daughter and I went to the location, but we couldn’t find it. Then he arrived, asked for my sister’s name, and which he remembered. He quickly looked and found a stone with her name, date of birth, and date of death. At this point he said a prayer. My sister didn’t have any love in life, but she did in death. In Judaism, when you go to a grave you leave a stone; I brought heart-shaped stones to put around her grave. We stayed at her grave for a while. In my mind’s eye, I saw a cloud, moving very fast with the wind, and it was slowly disappearing. I looked at my daughter and said: “I guess we can go now. She’s free.” And I have a sister, named Susan.

**Cullen:** That’s a powerful story, and I appreciate your courage in telling it. I’m struck by the powerlessness that people felt in institutions, such as Willowbrook and Pineland. I’m struck that we still have some of that feeling of powerlessness today. All of us are working together to offset the sense of powerlessness, and instead foster a sense of capability. Telling stories, like the ones we’ve heard today, helps fuel our determination and helps to keep us laser-focused on effecting positive change for people with intellectual/developmental disabilities. We’ll leave the Pineland story there, and we’ll see if Vanessa is able to join us in the future. We’re not going to get anywhere in the future without understanding our past. Thank you again, Deborah, for sharing your story with us!

**End of presentation.** *(Large 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:** Do 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’m disappointed to not have them here, and this marks multiple meetings in a row where we haven’t had representation from DHHS around the table. I’m willing to draft a letter on behalf of the Coalition to DHHS, requesting and urging their attendance at these meetings.

**-A motion was made and seconded, to send a letter on behalf of the Coalition to DHHS, requesting and urging their attendance and participation in the Coalition meetings.**

**Discussion:** The group was hopeful that an inviting message might yield positive results. It was stated that everyone, the Department included, has the same mission, and working together closely is mutually beneficial.

It was noted that the Department is a key player – providing information, hearing from us, and answering questions. Individuals, parents, family members, and providers have expressed frustration around waitlists, and the quantity and quality of services provided to people once they receive funded offers. It was stated that people around the table generally express their concerns in a very diplomatic fashion, and that experiences to the contrary have been the exception, not the rule in this regard. People having concerns about the service system for people with ID/DD should not be a rationale for the Department, which is supposed to provide services for the most vulnerable, to disengage from communication and information dissemination.

It was mentioned that Commissioner Ricker Hamilton has stated in hearings and other public forums, that communication is very important to him. We ought to communicate to Commissioner Hamilton that we would like to form a partnership that addresses some of the issues people have expressed, so that they can be addressed collaboratively and thoughtfully. This might be a way in which the lines of communication could be reopened.

It was stated that the OADS Strategic Plan mentions participation in the Coalition explicitly.

**Cullen:** Yes, that is right. After holding public hearings/forums, [OADS developed a strategic plan](http://www.maineparentcoalition.org/uploads/2/6/1/1/26115022/oads_biennial_plan_2017-2018.pdf), which was inclusive of the Coalition as a forum in which they could communicate and share information.

-It was noted that the Department hasn’t sent representation to other meetings consistently either; it doesn’t appear that the Coalition is being singled out in this regard.

**Peter Stuckey:** For some context, on my way to the meeting today, I was listening to the news which was discussing the Appropriations Committee holding a hearing about the expansion of MaineCare. Towards the end of the news story, it was stated that no one from the Department would be in attendance at the hearing, but would answer questions in writing. I think this group is small fish in a big pond, and what I have always appreciated about this group is its openness, and its enthusiasm in trying to understand all the forces at work in this world. I want to believe that the Commissioner is the person he presents himself as, but it’s astounding to me he would walk by an opportunity to take advantage of the knowledge, passion, generosity, and wisdom in this group. I come here without a personal stake, but because of all of you. It’s energizing, and it’s something I can hold on to, in a world in which feel-good stuff is hard to come by. I don’t think I’ve ever experienced a shouting match here. There’s passion and energy in the room, but it’s driven by a genuine desire to make things better in the world.

There was discussion about one time in which frustration was expressed at a Coalition meeting, on the part of Mr. Hamilton, and a member of the group. It was stated that Ricker appeared genuinely angry about this group, or partner members, not thanking the Department and the Governor for including money to the budget to support reducing the waitlist. There must be some kind of engagement where we can move past what has occurred in the past and work together. It was mentioned that being a commissioner that espouses social work values while being part of a political system must be quite difficult.

**Cullen:**  For people who weren’t here when Ricker attended and discussed that frustration, what was going on for me, as perhaps for others, was the Governor had presented an impossible dilemma – he put money into the budget for this vulnerable population at the direct expense of other vulnerable populations. Due to the manner in which the money for the waitlists was included in the budget, it was very difficult for me, and perhaps others, to support and applaud.

**-After discussion, the motion was approved unanimously.**

**Jennifer Putnam:** The Section 29 waiver amendment was reposted due to the scanning error and the public comment period was reopened for another 30 days. ([Click here for more information on the Section 29 Waiver Amendment Application, including information on how to provide public comments](http://www.maineparentcoalition.org/postings.html)).

The APS (Adult Protective Services) and Critical Incident System proposed rules were posted last week. With these rules, it appears to be a fundamental shift in the way abuse, neglect, and exploitation are handled in the state. It would be advisable for us to review this over the next few weeks, to examine the changes in reporting processes. My guess is that these changes are in response to the OIG (Office of Inspector General) report. ([*Click here for more information.*](http://www.maineparentcoalition.org/december-2017-presentation.html))

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

**Lauren Wille:** For those who don’t know me, I’m Lauren Wille, and I’m a Staff Attorney with DRM. I wanted to share a few updates. We have been dealing with clients who have been dropped off at emergency departments and then discharged from services by their agencies. These are people who, after being medically cleared to leave the emergency department, have no place to go, so they remain there. I think this highlights the crisis regarding crisis beds at the Department. ESM declined to renew their contract, which essentially cut the number of crisis beds in the state in half. This is having a major effect on this burgeoning, persistent problem. We’re also working on transportation. We’ve been encountering brokers denying clients transportation to eligible MaineCare services; brokers are saying they won’t transport a client without an escort. Six weeks ago, DRM represented a client at a hearing regarding this, which found that it is improper. It was found that once a broker has made the determination that the client is eligible for the service, the client can’t be denied transportation due to the lack of an escort. If there are concerns about safety, the broker is beholden to provide an attendant to ride with the client. This was one administrative hearing decision; it’s not binding across the board. However, we’re working with the Department to determine how this finding will affect other people to ensure clients aren’t denied transportation improperly. The DD Advisory Council is restarting, as DD Partners for Policy Change, for which the application process is now closed. The first meeting is scheduled in the very near future, possibly next week. We’re also holding visual gestural communication trainings: [December 13th in Augusta](http://www.maine.gov/dhhs/setu/forms/class-details.shtml?764575), and [March 30th in South Portland](http://www.maine.gov/dhhs/setu/forms/class-details.shtml?766678). Visual-Gestural Communication (VGC) is a form of communication that uses facial expressions, gestures, and body language/behavior.

**Federal Update:**

**Cullen:** I want to thank Bonita from Senator King’s office for being here today. For many months, this Coalition has been singing the praises of Senator King and his leadership and commitment to preserving Medicaid and services for people with ID/DD. As we’ve watched various threats to Medicaid, usually through attempts to repeal the ACA (Affordable Care Act), Senator King has been a champion for Medicaid and the people who depend on it for vital healthcare and services. Senator King has been fantastic. His [May 17th floor speech](http://www.maineparentcoalition.org/senator-king-senate-speech.html) was circulated widely amongst members of this Coalition and beyond. He has been responsive to our concerns, and his office has been sure to follow up with us. It’s been a long time coming, but I wanted to extend a thank you to the Senator for his outstanding leadership on that issue, among others!

**Bonita Pothier, Regional Representative, Office of Senator Angus King:** It’s an honor to be here. Our office is contacted frequently by members of this group as well as other parents dealing with the challenges of having adult children, or transition-age children, with ID/DD. These stories have profoundly affected Senator King. In terms of what’s happening at the federal level, and you know better than I do, we’re facing very challenging times. It’s taking a concerted effort to keep the eye on the ball because it’s being attacked in so many different ways.

One of the most recent ways is the tax reform bill. Senator King has repeatedly said one of the major problems with the tax bill is the massive increase to the deficit, because next year the big discussion is going to be “we can’t go forward with this deficit.” And what are they going to look at? Cuts to the entitlement programs. I’m here today because Teague Morris is on vacation, but he has alerted us to the work this group is doing, and asked us if someone could be here. We felt it’s important to continue listening to the stories, hearing the challenges, knowing what it’s like on the ground. It’s stunning. It is not unusual to hear people say, “What was wrong with the institutions we had?” This is alarming. And so, despite all the work you do, which is impressive, people still don’t know how to talk about the issues and lack the information to be able to make informed, thoughtful decisions. It is important that we maintain a connection, that we hear your stories, so we can look at what makes sense at the federal level to keep that forward momentum. We’re listening. It’s sometimes a real tough nut to crack. You have to peel away layers to maintain the integrity of the issues. I’m here to listen and pass your stories on to Senator King the best I can. Your voices matter. Your stories matter. Don’t stop speaking up. Sometimes you must bide your time to make sure you’re most effective, but you just need to keep up that fight, know that we’re listening, and will work with you to find solutions.

**Cullen:** I want to extend my thanks to the Senator for his most recent vote against the tax reform bill, and hope he will vote against the version that emerges from the Conference Committee if it continues to represent a threat to funding for housing, services, healthcare, and Medicaid, all of which we need for community inclusion. Non-Defense Discretionary (NDD) funding is clearly under attack in this bill due to the PAYGO requirements of the Senate, which would enact sequestration cuts, including cuts to HUD programs like Section 8 and the HUD 811 program, on which people with disabilities and other vulnerable populations depend. Then, entitlements are next on the chopping block, including Medicaid, Medicare, and Social Security. 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. This Coalition has spoken for the last 11 years about the need to have adequate funding for housing and services. We want to applaud Senator King for staying on the right side of this one. I hope that you and Teague will continue to attend these meetings, so we can learn from one another, and together design a system that will work well for everyone.

**Bonita:** Teague’s role is more statewide. My role is more regional; I’m in York County, but I’m glad that I’m here today.

**Cullen:** The more we all share information, and stay updated, the better we’ll all be. While we’re on the topic of the tax bill, I’ll move on to talk about Senator Collins. She supported Medicaid during the attempts to repeal the ACA, and voted against an ACA repeal bill which would have decimated Medicaid funding. The tax bill’s effect on Medicaid seems to follow suit; however, Senator Collins voted for the Senate version of the tax bill, with what she believes are assurances. I’ve received information to the contrary; there is no mechanism to protect Medicaid from the effects of this tax bill. The Conference Committee is working on reconciling the versions of the bill passed by the House and Senate, and will be looking to finalize the bill as soon as possible. Congress quickly passed a two-week Continuing Resolution (CR), funding the government through 12/22, quickly perhaps so they could continue to work on tax reform. It is urgent to reach out to Senator Collins with the message that it’s important to have the resources we need for housing, services, and healthcare. I have good relationships with people in her office, and yet I’ve been unable to reach any of them. It appears the only way you can get through the phone-tree system is to leave a message. I encourage everyone to reach out individually to Senator Collins. Send a letter saying why it’s important to have housing, healthcare, and support services, all of which appear to be in jeopardy in this tax bill. You can send an email (Kate Simson, [Kate\_Simson@collins.senate.gov](mailto:Kate_Simson@collins.senate.gov)), or submit your messages through the Senator’s web form (<https://www.collins.senate.gov/contact>). It’s important for Senator Collins to hear from us so she can to make the right choice when she votes on this bill. Bonita mentioned the effect the tax bill would have on the deficit – it would add anywhere from $1 trillion to $2.2 trillion to the deficit over the next ten years. This is alarming.

-It was stated that there are other alarming provisions in the bill, including making political campaign contributions tax-deductible.

**Cullen:** There are numerous provisions in the tax bill that will only benefit wealthy individuals and corporations, many of which were included in the bill to gain sufficient votes for its passage. One example is a tax cut for owners of private jets.

-A self-advocate stated that the majority of people’s life experiences with ID/DD are out of sight and out of mind. She stated that most people with ID/DD, apart from herself, aren’t out there advocating. Many people from Pineland have died; their stories will never be told. People’s stories aren’t being heard, that’s why we’re here advocating.

**Skip MacGowan:** Then Governor King was in office when Pineland closed. The votes on funding Medicare and Medicaid are important. However, I’m interested in seeing an expansion of options under the waiver. The waiver is based on a more than 40-year-old law, and is very strictly defined as an institutionally based model. This needs to open up. There is a need for a broader definition of care, of community care. There’s also very little in the way of technology being used to offset staffing. It’s time for the government to rethink the way services are provided. Services must change with the times – this is a way to do it better, do it right, and save money at the same time.

**Bonita:** Thank you for your comments. Technology is big for Senator King. We have someone on staff whose primary role is focused on technology – to look at better utilization it and expanding its reach. What you’ve mentioned speaks directly to why technology is so important.

**Cullen:** Bonita, thank you for being here today. Please join us whenever you can, this has been a great opportunity to have an open dialogue, for which we’re very grateful. Thank you again, and please pass on our thanks and admiration to Senator King!

**State Legislature Update**

**Jennifer Putnam:** The Maine Association for Community Service Providers ([MACSP](http://meacsp.org/)) put in a late-submission bill seeking to increase the rates for Section 28 children’s services. 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. New bills in the second legislative session go to Legislative Review, and then an appeal hearing if needed/requested. There was an appeal hearing on November 30th, where many bills were considered. Our legislation won’t be decided upon until January. We’re optimistic, and the Department is in support of this as well. There are a couple of bills that were accepted that are of interest: Representative Parker’s LR 2704, An Act To Allow the Maine Developmental Services Oversight and Advisory Board Access to Investigations of Suspicious Deaths and Mortality Reviews Performed by the Department of Health and Human Services; and Representative Denno’s LR 2500 An Act To Reestablish the Office of Advocacy within the Department of Health and Human Services. It does not appear there’s a lot of appetite to reestablish the Office of Advocacy, but there is a possibility of combining that bill with Representative Parker’s to hopefully address issues brought to light. Funding for year two under LD 967, the bill that increased the rates, has been carried over. We’re hoping to address the second year of funding and institute an annual review going forward. We hope it will put us back to the 2007 rates, plus some adjustment for inflation. From my conversations so far with legislators, it appears they’re looking forward to finishing the job and felt the one-year funding was leaving things undone. We’re feeling optimistic that the basic rate increase will be funded through the full biennial budget.

**Rachel Dyer:** The Department has discussed moving Child Development Services (CDS) into the Department of Education (DOE). Numerous questions remain unanswered about how it would work, and whether schools have the capacity to take this on. A plan should be put forth to the Education Committee in the near future.

**Announcements:**

* SPARK is hosting a free showing of *Life, Animated* at the Dana Health Education Center, Maine Medical Center, 22 Bramhall Street, Portland, ME on December 18th at 5:30pm. [Click here for more information.](https://mainehealth.org/maine-behavioral-healthcare/research/spark)

The next meeting will be on **January 8, 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).***