September 11, 2017

Minutes

Present: Kathy Adams, Frances Ryan, Misty Niman, Jenn Brooking, David Cowing, Debbie Dionne, Kim Humphrey, Ed & Suellen Doggett, Emily Haugh, Nonny Soifer, Charlene Kinnelly, Liz Weaver, Noel Gallagher, Eric Russell, Catherine Thibedeau, Jamie Whitehouse, Gil Moreno, Patrick Moore, Erin Rowan, Alli Vercoe, Julie Brennan, Paula Schrank, Jerry Silbert, Lydia Paquette, Lauren Wille, Bonnie-Jean Brooks, Margaret Cardoza, John Regan, Peter Stuckey, Skip MacGowan, Cullen Ryan, and Vickey Rand. Via Zoom – Bangor (UCPofME): Elizabeth Whitmore. Winthrop (Autism Society of Maine): Cathy Dionne and Emily Kalafarski. Sanford (Waban): Morgan Jones. Auburn (John F. Murphy Homes): Ann Bentley and Darla Chafin. Brunswick (Independence Association): Ray Nagel. Orono (CCIDS): Bonnie Robinson. Waterville (Waterville Public Library): Pam Cairnie. Misc. sites: Stacy Lamontagne, 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: Skip MacGowan. Topic: Part one: A review of the history of the system of care for people with intellectual/developmental disabilities, including Pineland, and how people are working to archive and preserve this history.**  *(*[*Click here for an audio recording of the meeting, including the featured speaker/presentation*](http://www.maineparentcoalition.org/september-2017-presentation.html)*)*

**Cullen:** Today’s presentation is the start of a three-part series on the history of the whole service system. We have done this before in three different incarnations, but they were stretched out over our 11-year history. It’s time to really dig in and find out what happened during the Pineland years, what happened afterwards, and what a group of people did to change the system.

I’ve had the pleasure of hearing Skip present this history with the MDSOAB (Maine Developmental Services Oversight and Advisory Board); you’re in for a treat. Skip worked at Pineland and was working to make that work well, but within the system he also worked to ensure the needs and desires of people with ID/DD were met as the head of the DHHS Advocates, and as part of the Consumer Advisory Board. He now continues that work with the Maine Developmental Services Oversight Advisory Board.

**Skip MacGowan:** Today, I’m going to try to just cover some of the history; that’s enough for the time we have. I’ll try not to preach, but I start talking about this stuff and I get angry again. However, I’m going to try to present an honest history. There are people here who will be able to correct any errors I make, and contribute with their own histories. I want to preface this presentation by saying I’m going to use language that I would never use personally, but it’s the language of the law.

A lot of the beginnings of Pineland had to do with the eugenics movement. Eugenics is to genetics what alchemy is to chemistry – which is to say there isn’t much of a connection. It was a “genetic” theory that “feeblemindedness”, mental illness, poverty, and a host of other “societal evils” were caused by genetics. This movement was truly wrong. The theory was that there was a need to stop the pollution of the gene pool. Prior to 1908, Maine’s system of care didn’t exist. Care was provided by families, and when families got to the end of their proverbial ropes, they went to the poverty offices in towns for help. This system didn’t work well; it didn’t work for anybody who needed the care, especially. This was not a good way to provide treatment. This was a way to get people into the workforce, or nothing. By 1908 the towns were saying this isn’t working for us; town farms weren’t working well for years. The Legislature agreed to establish a school for children, the Maine School for the Feeble Minded, and the original, enabling legislation was for people 3 to 21 years of age. *(Note: The Maine School for the Feeble Minded went through a number of name changes. It became known as the Pownal State School in 1925, then the Pineland Hospital and Training Center in 1957, and inevitably Pineland Center in 1973, or more commonly known as simply Pineland. For ease of comprehension, these minutes simply refer to all of these different incarnations as ‘Pineland.’)* The expectation was that these individuals would have training and support to become self-supporting. These appeared to be all noble, good intentions. As is the case almost throughout Pineland’s entire history, the intent was a good one, but there were unintended consequences. At any rate, by 1908, when the legislation was enacted for Pineland, people anticipated its opening and a waitlist formed. I’d like to say that there were good intentions, but it doesn’t appear that way as much as it should. The 3 to 21 age group disappeared almost instantly, and within two years it had been abandoned. People had to meet a means test, proving whether they could provide something of value to Pineland to offset costs; if people couldn’t, they weren’t accepted. That’s unbelievable. This was the way it was from Pineland’s inception until about 1920 – in order to be admitted to Pineland, they made sure people could work on the farm.

Pineland looks like a small college campus, it’s beautiful; now, it’s even more beautiful as the “new Pineland.” It was a nice location, it had a farm, a work area, and if you applied for Pineland they determined if you could work on the farm. And, people did work on the farm; they didn’t get paid but it offset the cost of care. For young girls, they had sewing and had a lot of training in domestic activities. A lot of the girls, even when I first started working there in the early 70s, were being placed out of Pineland as maids; the Superintendent had his own maid.

The population at Pineland began to increase; over the first couple of years it went from 57 to 62 people. Then came 1912. Malaga Island, an island in Phippsburg, was populated by a mixture of people who didn’t want to live in normal society and who were happy to live separately. The locals had become gentrified, to the point where the locals were offended by this group of people, and there was a request that they be removed from Malaga Island. Inevitably this happened. The Legislature closed the island and moved everyone; a very large percentage of the people relocated from the island, including inhabitants of the cemetery, were moved to Pineland. The population at Pineland before this occurred was 62; between then and 1914 the population at Pineland increased to 172, many of whom were former residents of Malaga Island. When this was occurring, there were no tests for admittance; these people were simply shipped to Pineland. Pineland became a catch all for people with a variety of needs, because there was nothing else. Pineland took in orphans; almost anybody who was not wanted in general society. This was not Pineland’s wish; this is one of the many unintended consequences. I suspect most of the people who worked at Pineland were like you, they care, they wanted to do the right thing. However, wanting and doing are very different, and having the wherewithal to do things right is often very difficult, even now. I suppose it was the good times for Pineland in terms of trying to meet a mission that made sense at the time. Unfortunately, it wasn’t meeting the needs of many families.

These practices went on for about 8 years. Families were beginning to say “my child needs care, not work.” It was all fine and good that there was a school and people were receiving training to be “self-supporting,” but what about people who need more care than that? By 1922, there was a paradigm shift; there was an increasing acceptance that people were going to need care. This shift was part of the genetics movement, the thought that separating and isolating people with special needs from the rest of society was best for everyone, and that they would be happy with their “own kind.” And, starting in 1920, people needing care were accepted into Pineland. Starting in 1920, people who were higher functioning, the “high grades” starting caring for the “low grades.” It was work. It doesn’t sound as evil as it was. There was a lot of training. It was kind of hit or miss, and the care was clearly mainly custodial – less than that, more often it was janitorial care. I saw that in 1970; there was still an awful lot of janitorial care rather than treatment. By 1920, Dr. Vosburg, a proponent of the eugenics movement, took over as Superintendent. He believed that Pineland needed to expand to take in these people. With his support in 1925, the state passed a sterilization law, being the 25th state in the country to do so at the time *(Maine’s 1925 law provided for the sterilization "for eugenic purposes or for therapeutic treatment on feebleminded and others suffering from certain forms of mental disease, " and the 1931 law, which amended the original 1925 legislation, referred to residents of any institution for the insane or feebleminded.)* Per the law, people in the institution needed to be sterilized before being placed out. This was a very slippery slope. The thought was that people who couldn’t care for themselves, shouldn’t have children because they wouldn’t be able to care for them either. Also, that they shouldn’t have children because their children might also be “slow.” Most of the people pushing eugenics were doctors, judges, and lawyers. The same year this law was passed the hospital at Pineland opened. It’s very difficult to talk about this.

By 1925 the population had gone up to over 700 people. There was a clear growth factor of people needing care versus people who could provide care or work the farm. More and more people were working or caring for other residents of Pineland, and the thought was that they needed more capable people to care for less capable people. This pushed the population explosion. The window of opportunity to place people at Pineland broadened. Staffing at Pineland up until 1972 was hovering around 200; however, this number is misleading. Pineland was a community, a small town, with groundskeepers, laundry staff, supervisors, a kitchen serving an ever-increasing group of people, a transportation system, dining hall, and so on. When you actually whittle out all of the staff who were supporting the community at large, the number of people caring and treating residents of Pineland was remarkably small. By the 1940’s the one thing that was crystal clear was there were more people in need of care than people able to provide it. Accounting for the 50 staff who might have been doing some sort of care or supervision of care, the average staff-to-client ratio was 1 to 36 at the best, 1 to 50 or more at the worse. This was that case even into the 1970’s.

I’ve covered a lot of history, but this is a good segue into the story of my first experience with Pineland. I dropped out law school and the only thing I thought myself capable of doing was possibly teaching. I was 22 years old at the time. Someone told me that Pineland always needs teachers. Mind you, Pineland’s use of the word “teacher” was quite questionable. I went to Pineland, spoke to someone on staff, and said I was looking for a job. I met the head of the adult unit who was a nice well-meaning man, I’m sure, and he said “sure, I’ll send you down to the building you’ll likely be working in.” He sent me down to Cumberland Hall I think; one of the adult halls. I approached the building, which was a nice building, with big pillars, and I went to the door. It was locked. The buildings built at Pineland were cruciform in their layout, so when I looked in the window on the door, I could see down that hall. I saw that there were people at the far end of the hall. I rang the doorbell and a man came out, looked at me, and screamed “thank God you’re here! I haven’t had a break all morning.” He ushered me in, got out some keys, opened the room, and let me go in first. When I turned to him he said “the bucket, mop, and shovel are by the door. Don’t turn you back on anyone. I’ll be back in 15 minutes.” Then the door closed and he was gone. I checked and the door was locked – I had become an inmate too. The room I was in in had cathedral ceilings, and was almost totally bare, save for two benches along one wall, and two chairs on the other side of the room. It was a very large 20’x40’ space, with 51 people in it. The mention of the bucket, mop, and shovel by the door should’ve given me a clue about what they thought “teaching” was. About one-third of the people in the room were sitting on the floor, the rest were milling about. A number of the people were spinning in hospital johnnies; most were naked. It was very disturbing. The first time you see a site like that you’re taken aback. About 15 minutes passed and the man who let me in hadn’t returned. I was beginning to fall apart at the seams. After about 10 more minutes the man returned. I said “I was just visiting the hall to see where I’d be working if I accepted a job here, which will not be happening.”

I left the hall and went to talk to the team leader of the adult unit. I hesitate to say this, but I did say it so I will; I said “you’re running a concentration camp. This is criminal.” He laughed a little and said, “you college kids are all alike, what did you expect? This is all we can do.” I think he would’ve liked to have done better. I replied “not only am I not taking a job, but I’m going to start contacting everyone I know and tell them you’re running this horrible place.” He said “go down the hall and talk to the Bannister.” Confused, I went down the hall, and saw the name Art Bannister above a door. He worked with children and youth. As I got close to the door, he came rushing out and said, “you applied for a job. You didn’t take it, did you? We’re running a program that’s different. We do real teaching, I think you’d be okay.” He offered to show me, and after the shock of everything else I said that I’d take a look. He took me to Pownal Hall, the children and youth building that had been most renovated of them all. Two wings in the building I first visited were lined with beds, with not much space between them, to accommodate the 50+ adults. Pownal Hall was altogether different; it was divided and had cubbies. There was a living room area in one corner of the big room, with a television. Each of those units had maybe 12 people, 16 people at the most. It was small enough to look around and see people. He took me into the first unit which had 5 to 10-year-old boys. When I went in the room, there were three staff present and they were doing things like tying shoes and teaching people to tie, one was reading a book to someone. He said “see this is nice, isn’t it? You’d like to work here!” This atmosphere was more like what I had expected. He asked if I could start in an hour and a half; I said no, that I could start the next day. He told me to be there at 6:45am and everything would be fine.

I misinterpreted a lot of what was going on in Pownal Hall on my first visit. It was noontime, so there was a change of shift happening, and it was payday, so people were getting checks. The next morning when I arrived, I discovered I was alone with 14 to 15 people, and I was working with the older, active boys as they called them – they were basically teenagers, some young teens, up to about 16 years old. My first day was difficult. I went into the unit, and I was told get people up, dressed, and ready for breakfast at 8:15am. I spent the entire time putting socks on people, tying shoes, buttoning shirts, cleaning people up, stripping beds, and when it got to be about 8:30am – yes, I was late my first day – I got the boys downstairs. When I was asked, what took so long, I said it’s hard to get everyone dressed. The reply I got was “why’d you do that? They can dress themselves.” Come to find out almost all of them could. It was a very interesting first day and first week; it changed my life for the better. In retrospect, in terms of self-satisfaction with a job, it may have been the nicest job I ever had; you could go in and do something and you could see the benefits.

-It was asked if Skip could expound upon the reason why individuals were having him dress them.

**Skip:** Yes; I will tell you the reason and how much that reason means. Staffing ratios were low. Think about working somewhere where there’s 50 people your charged with essentially being their janitor. People need attention; we all need attention. Think about a life where you’re ignored. In Pineland, people would do whatever it took to get attention. The thought was “if he’ll talk to me and tie my shoes that’s nice, so I’ll let him do it.” The worst of it was, people would bang their heads until they bled, because if you bled someone had to deal with it. Think of how desperate people were for connections to go to those extremes.

-It was stated that there was an actual school at Pineland.

**Skip:** Yes, there was a school there from 1912 to 1920, and by the time I was there the school was there. It was a wonderful place, but it was also sorely understaffed to meet the needs of all the people there. Some people think, education is something that people need until they’re about 20 years old. However, this is something that people do all throughout their lives; this is especially true for people with ID/DD.

The reality is attention-seeking behavior ran rampant. I might as well go through the other evils of the way Pineland operated. The caring of clients by clients led to power struggles. Power is something we address all the time. In an institution, any modicum of control or power was important and there were, through no fault of their own, clients who dominated other clients; they used their size, weight, and strength against others. One of the things that institutions do very poorly is socialize people. Social norms by their very nature are norms. If you take all of society and bring it down to a point, on one side of this is abhorrent behavior, and the other behavior considered normal. The norms in an institution are not like those of society, thus they do not prepare people to live in society. When I got to Pineland, I don’t think there had been a lot of effort to involve the residents in formalizing toilet training, hence the bucket, mop, and shovel in the building I first encountered. There were basic things that you had to try and teach, and there wasn’t a great deal of supervision for the teachers, so people did it on the fly, with the thought that it was better than the alternative. For instance, if you took a group on a walk around the grounds, and someone had to relieve themselves, you would try to direct them to a more private place, and then let them do it right there on the grounds. What is this teaching people? This is teaching people that wherever they are if they need to relieve themselves they can, because it’s better than the alternative of wetting themselves. There was no malice behind this, it was simply better than the alternative. This was, however, short-sighted if the hope was that people would live in community settings and do well.

Learned behaviors became significant obstacles to community placement. Attention-seeking behavior doesn’t go away because there is better or more staffing; it’s a learned behavior. That’s one of the lessons about institutions – they are not places to teach people how to live in society; that needs to be done *in society.* After I got to Pineland, 98% of these practices changed due to the development of treatment in the community, which began around 1970. Prior to that, there were community placements, but they were very different from what we would consider community placements today. In the early 1950’s, Pineland got yet another Superintendent, Dr. Peter Bowman, who came in with lots of cool words attached to his name like deinstitutionalization. It was a wonderful thought, but deinstitutionalization wasn’t all it was cracked up to be. By the mid-1970’s I was investigating complaints in the community. I received a call from a farmer in Vassalboro who said his Pineland “community placement” of 22 years couldn’t work on the farm anymore, and asked if I could come pick him up. I went to talk to him, and come to find out he wanted to “swap.” I explained that what he had been doing was essentially slavery, and that had I known about it sooner I would’ve put an end to it. At that point in time, 90% of “deinstitutionalization” were “work” placements, where the people received no pay and were essentially treated like slaves.

The 1940’s were a key time in history. Any effort to pretend that the work was farm labor and teaching people to do jobs in society had gone away. The thought was that they needed more people to care for people. This affected outplacement. It’s easy to imagine people sitting around going “we can’t let her go, she’s great on the unit.” If you placed people out who were capable, there were fewer people to care for others. As such, efforts to place people out in the community weren’t as good as they should have been. And the staff were like saints; this is not a job you do to get rich. When I started as an aide, the aide with me had a child and wife, and he was collecting his salary along with food stamps because he was paid so little. However, they cared so they did it anyway. I’m sure that the staff were doing the best they could with a bad situation. What was the bad situation? It was funding. This isn’t anything new; this always seems to be the problem. Funding was a continuous problem. I’m sure that’s what drove the need for keeping very capable people, in some instances people who never should have been at Pineland, in the institution when they could have been placed in the community. Due to lack of paid staff, to provide any level of reasonable care it was mandatory to have clients provide care for other clients. Was this right? Absolutely not. Was is necessary? At the time, it was sadly the most they could do.

Throughout all of this history there were families. These were families who were told by their children’s doctors to put their children in institutions, which were equipped with professionals who would know best how to provide care for them. Families believed the doctors, they had no reason not to – they were professionals. However, families didn’t simply send their children to Pineland and then go, “all is taken care of.” I’m sure there were many families who were saying “why is my child not getting better?” In some cases, their children may have been getting worse. When families would inquire about how their child was doing, the response from staff was that they couldn’t talk about it or that the child was doing fine. That a natural response – you don’t say I’m trying and I’m lousy, but this is the best I can do. Anything that was manufactured to describe Pineland, such as the annual reports to the Legislature, put a good face on the conditions. Sometimes there was an honest attempt to get more staffing. By 1938 there were 51 buildings at Pineland; they successfully petitioned for money to physically build buildings, so there was in fact money, but not money for staffing and treatment. Then World War II (WWII) started, and things began to change.

More than 70 people were drafted out of Pineland to serve in WWII. One could speculate, and likely rightfully so, that maybe those people were capable and shouldn’t have been at Pineland to begin with. All throughout this period people tried to escape – and, why wouldn’t they? If you were capable enough to recognize how bad it was, you wanted out. A number or people got out, some of whom were caught, and their heads were shaved so they could be recognized in the event they should try to escape again. Due to the more capable, higher functioning males people being drafted to serve in WWII, the quality of care took a major hit, because these individuals were providing care to the less capable individuals. After the war, parents became more assertive, they started asking more questions, and in 1947 the first outside investigation of the quality of care at Pineland was commissioned by Governor Payne, at the suggestion of the Maine Federation of Women’s Clubs. This investigation resulted in a rather critical report in 1951, which detailed the conditions at Pineland, among other findings. The report found that staff were trying to do their jobs, but doing them poorly due to insufficient funding. This report had an effect. The Board of Visitors was formed, which was the first step to allowing families to have some insight into what was going on inside the walls at Pineland. If there’s enough interest, when parents get together and get angry, they can do anything. Families demanded that Pineland be upgraded, and provide more than just custodial/janitorial care for their loved ones. This happened, to the degree Pineland could make it happen, but it wasn’t like the money spigot was turned on. However, there was interest; people were saying the conditions at Pineland weren’t adequate. People wanted information, they wanted to know what was going on. However, confidentiality was used as a reason why details couldn’t be revealed; this justification becomes a good way of avoiding providing explanations. But, somebody has to be able to look over the log and be able to report back. Parents must be able to say “this doesn’t look right,” or, “this ought to be changed.” If you can’t see over the walls, you can’t do that. A few years later, Pineland Parents and Friends was founded, a group of parents who got together once a month, met with administrators, and advocated for change. They did a lot. They also asked a lot of questions. There was an evolution of parents asking questions, to parents making demands, to parents wanting to be involved with hiring staff. This led to the most dramatic changes at Pineland.

Roy Rogers was my hero as a kid. Before the Kennedy’s came out publicly and said they had a child with a disability, Roy and Dale Rogers said the same thing on television, at a time when it wasn’t easy to do so. They said that they loved their daughter just the same, that she was a real person, and that she needed help. They did that on national television, and it was an incredibly brave thing to do. This was when a lot of parents started saying “yeah, I can speak out too.” This evolution changed pretty much everything. In 1961, President Kennedy came into office, and among the first things he did *(at the urging of Eunice Kennedy Shriver),* was set up a panel to review the needs of people with ID/DD. Within a year, that panel came back with over 100 recommendations for immediate action. One year after that, the Maternal and Child Health and Mental Retardation Planning Amendment to the Social Security Act, the Mental Retardation Building Act, and a number of other bills were enacted, all of which were funded through Social Security. This meant that the money started to flow. That was the beginning of the end of Pineland – but we’ll get to that. Money started flowing, and opened up a lot of things. The press got involved, at the insistence of parents trying to get information out to the general public. The most important thing someone can do to fix the system of care is to talk about the system of care. A lot of people didn’t know there was something that needed to be fixed. During this time, additional, higher quality buildings were built at Pineland, designed to be more practical. Additionally, Pineland received hospital accreditation in 1963, which lasted until 1970. During this time, Pineland was led by Superintendent Bowman, who was a large proponent of the medical model. I’m not sure if this was good or bad – it might have been a step towards something better, as things were regimented, people wore uniforms, and it was very rigidly run. People were being placed out of Pineland, and the population went down some. However, most of the placements were “work” placements. When Superintendent Bowman “left” Pineland, he was escorted off the grounds. However, Bowman was pretty good with the Legislature. Bowman was very capable and built relationships with legislators. He told them what he could do with adequate funding, and due to these efforts, Pineland got direct funding from the Legislature – it wasn’t funded through any specific Departments. Things got marginally better, but just trying can make things better – similar to the Hawthorne effect, or the awareness of being monitored, and the alteration of behavior due to this awareness. The improvements were not significant, though.

By 1973, Daniel Hiscock of the Lewiston Evening Journal wrote an 65th anniversary article on Pineland titled, “[Pineland Center Has Come a Long Way in 65 Years](https://news.google.com/newspapers?nid=1913&dat=19730929&id=kAgiAAAAIBAJ&sjid=n2gFAAAAIBAJ&pg=834,3917736&hl=en).” The article raised many issues which angered many people. Many Pineland parents lived in Lewiston. Basement schools and day cares for people with disabilities started in Lewiston, there were a number of them around, and they were very dedicated people doing an awful lot of work. Due to the press coverage, there was an increasing desire for parents not to send their children to Pineland; people were saying no to doctors when it was recommended and would instead opt for the growing number of community options. Then came 1975, the watershed year when Pine Tree Legal filed the class action suit. This filing was part of a nationwide movement; the civil rights movement propelled the women’s movement, which propelled the disability movement. When Pine Tree Legal filed, I think there was a level of complicity of legislators, administrators, Pineland administrators, judges, the Attorney General, the Governor, the Governor’s wife, and so on. Ellen Longley, the Governor’s wife, was involved with groups of women who were concerned about Pineland, and she brought her concerns to Governor Longley, who took it seriously. Would things have changed absent Pine Tree Legal filing that suit? Probably, but not in the way that they did. Between 1975 and 1978, there was this kind of conspiracy to put things together in a way that would benefit the clients; it happened, and it was remarkable. Pineland’s population started to decrease, and staffing ratios started to increase. By around 1980, the staff-to-client ratio was equal, and moving forward the staff population was greater than the clients. People were getting pretty good treatment, people were getting placed out of Pineland, and there were growing community options. It was a wonderful time. People began approaching those family groups who established schools and day cares in basements, which proliferated during this time, suggesting they open small group homes, and they did with help from the Department. Things didn’t always work, but people were willing to try. From 1978 to 1985 things markedly improved. The original Court Master, David Gregory, was amazing; he was a very nice guy, but he could be brutal. He was exuberant in his desire to get this done, which was nice, but it was very hard on people. We are talking about changing people’s lives in major ways, undoing years of dysfunctional training, and so on. I’m going to stop there because the next thing we’ll talk about is the Decree and the Consumer Advisory Board, the way it came together, and the way it could still come together if people push for it.

I should mention that I’ve only touched on the edges of the horrors that occurred at Pineland. A community that cares for vulnerable people will attract a small percentage of predators, and believe me there were some predators on staff who were despicable. I didn’t even know what was going on at that time because it was so engrained in the system. When a staff person told a client to do something, such as mop the floor, if the client put up any argument staff would take their glasses off as a warning sign. If the client still didn’t comply, staff would keep going and take off their watches – this was a warning that if the client didn’t obey he or she would be beaten. Obedience was by pure coercion of power. Clients were petrified simply because someone took off his or her glasses, because they knew exactly what it meant. That could never have happened if people could peak behind the curtain at Pineland, if light had been shone on the situation. When I got there, families were prohibited from visiting units; that was a way in which Pineland administrators could control things. How do you stop that? You shine the light on it. You create a system that allows parents, consumers, community, press etc. a portal into the reality of the system. This portal started with Pineland Parents and Friends; this was the beginning of people having a dialogue. Families insisted that they had a right to know what was going on, and that was the best thing about family involvement. Pineland Parents and Friends insisted on having a representative on Pineland’s hiring committees, and it happened. People began making demands, saying that it isn’t good enough, and that they needed more insight. Importantly, the more families had input into hiring, the more allies they had on the inside who would talk with them; those relationships made all the difference in the 1970’s and 1980’s.

I was once in a group like this where I think Ron Welch (former Director of Adult Mental Health Services for DHHS) asked everyone around the room to express their wishes. Everyone around the table did; everyone there, mainly parents, had such great ideas. Then it got to me, I was last, and I said my greatest wish was just enough, enough of everything; shoes for the shoeless, food for the hungry, homes for the homeless, we just need enough. It’s not an easy request, but we need to say that there is a societal norm, there is a bottom line under which we cannot go. Things have a way of devolving. Some of the best of systems I’ve ever seen were in Maine in the early 1990’s; it wasn’t perfect but we’ll never be perfect. The problem is, someone came into a leadership role who didn’t understand the system is fragile and an ongoing task. It then became just maintaining, and soon it was “if it doesn’t get too bad we could save some money,” after which an inevitable system collapse occurs. My biggest fear is the work of a generation of families will be undone. Life is a complex web, woven very finely, and it takes a lot of levers to make everything work right and well. That’s what we should ask for – enough. Enough money to do it right. Enough money to get quality staff and keep them. Having worked direct care and loved it, I know firsthand it’s a grueling, tough, demanding job. If you do it well and want it to work, it requires intelligence, patience, and insight, things that are hard to buy, and you surely can’t buy them with minimum wage.

*(Round of applause).*

**Cullen:** Thank you Skip, for an insightful, thoughtful presentation. Before we go into questions and answers I wanted to check if any representatives from OADS have joined us at any of the remote sites. *(Emily Kalafarski waved from the Winthrop site).* Thank you, I’m glad you’re here! This group is very eager to hear what’s going on at OADS. First, let’s take a few minutes for reactions from the group. This is a lot to take in, and very difficult to hear. The hope is that revisiting this history will allow us clarity and help us all to shape the future of the system of care.

**Discussion:**

-It was stated that, though extremely hard to say, at the time slavery (the “work” placements) was preferable to prisons – and that is exactly what Pineland was. After parents admitted their son or daughter to Pineland they didn’t have the legal right to withdraw their child. People could be fined serious money for aiding and abetting the “escape of an inmate.”

**Skip:** I grew up in Maine. In the late 1950’s and early 1960’s, the civil rights movement was major; in Maine, it was hard to understand what was going on the national scale, but you knew it was important and groundbreaking. The same is true for the disability movement. It seems almost unreal that this was like a separate society taking place around us; it was out of control, to no fault to the people who were trying to make it better. I did numerous rights trainings for clients, families, and staff. While going over people’s rights, it seems silly saying it now, but I covered things like having nutritious meals spaced appropriately throughout the day. Pineland had all its meals in an 8-hour block to conserve staffing. Staff would bring in snacks and juice because clients were going hungry; it was appalling and hard to imagine today. People didn’t have adequate access to toothpaste and deodorant. When I started providing direct care, there would be little nubs of toothpaste available, and when they were completely used, and people would ask for more they wouldn’t be given more until the first of the month. Staff would bring in toothpaste for clients. When my status was elevated and I became an Advocate I inquired about the toothpaste situation. Come to find out, there was an entire storeroom filled with items such as toothpaste; it wasn’t distributed due to fear that it would be stolen by direct care staff. Well, staff were spending their own money on toothpaste; they weren’t going to steal it.

-A family member stated that her sister went to Pineland when she was around 8 to 10 years old. She needed an extremely high level of care. The family was told that they couldn’t visit for six weeks. When the family finally could visit with the staff, who were wonderful, they discovered that at the time the thinking was that she should learn to drink out of a cup on her own. However, she couldn’t do that because she can’t swallow properly when drinking from a cup, so she didn’t. When her mother saw her sister for the first time, a child that she didn’t want to send to Pineland, she was appalled as she had lost an enormous amount of weight; her mother commented that she looked like a Holocaust survivor. She never recovered from that sight, that image. Her family, including the family member as a child, visited, saw the halls, and never recovered from that experience. The trauma experienced by families is real and ongoing.

**Skip:** I’ve talked with some lovely families who were traumatized, but who were also tenacious and fought for what they needed. Grace worked all her life educating people about what was needed; she was still advocating when she was 90 years old.

-A member of the group stated that one of the powerful influences for the disability movement was Ralph Nader, who exposed what was going on inside institutions; he got the wheel going for exposing the truth. [*Christmas in Purgatory: A Photographic Essay On Mental Retardation*](http://www.disabilitymuseum.org/dhm/lib/catcard.html?id=1782), by Burton Blatt and Fred Kaplan, originally published in 1965 (republished in 1974), illustrated the appalling conditions at eastern state institutions. This photographic essay was essentially an exposé which revealed the truth. It’s important to remember, and it holds true today, if people were not broken going into Pineland, they were upon release. It was stated that the institutional conditioning was very, very effective – and particularly traumatizing. A self-advocate stated that from her position, from her own perspective, there were three models: The moral model, where people with ID/DD were evil and had to be destroyed; the medical model, where people with ID/DD were “broken” and had to be “fixed;” and finally the societal model, propelled by the rights movement, where it was finally recognized that there was nothing “wrong” with people with ID/DD, the general population just didn’t have proper information about and experience with people with ID/DD. The latter, can only happen in the community. The medical model was very powerful, and very destructive.

-[Burton Blatt](http://bbi.syr.edu/about/who_was_burtonblatt.html) also served as Dean of Education at Syracuse University. He was a pioneer for improving services for people with ID/DD, a strong advocate for deinstitutionalization, and a leader for Special Education. Among numerous other pieces, he wrote about the educability of people with ID/DD in the 1920’s, where he established that anyone can learn; before this it was a consistent thought that people with ID/DD were incapable of learning. For *Christmas in Purgatory,* Blatt would fasten a camera to his belt buckle in order to take photographs inside institutions, because at the time it was against the law to do so. It was only after this photographic essay was published that the New York Legislature believed that there were abuses going on inside institutions in New York state; legislators had heard about the abhorrent conditions, but the claims were not believed until that essay came out.

**Cullen:** Skip, thank you very much for your time, this was incredible. Skip will be back again with part two of this presentation next month, so I hope to have great attendance!

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

**DHHS Updates:**

**Office of Again and Disability Services (OADS):**

**Emily Kalafarski, Associate Director, Disability Services:** We are in the final stages of the internal review for the Chapter III emergency rules for both Section 21 and Section 29, which includes the rate increases for the vast majority of services, as well as the doubling of the Section 29 cap. We’re hopeful that it’s a matter of a few weeks until these are proposed.

**Cullen:** So, we might be talking about seeing these changes actualized within a month or two.

**Emily:** I can put a specific timeframe on it right now, but we hope so, and we are talking weeks not months.

**Cullen:** That’s very encouraging to hear. Is there anything else we should know about the rules, or anything we can do to help this process go smoothly?

**Emily:** We’ve received a lot of questions. Because these are being proposed as emergency rules, they will be provisionally accepted right away. We have to wait for the rule to be proposed, but once that happens we’re ready to respond to new service authorization requests.

-It was asked if the Department must receive approval from CMS ([Centers for Medicare and Medicaid Services](http://www.cms.gov)) through a waiver amendment before the changes can go into effect.

**Emily:** That will be retrospective. CMS is aware of the changes, but that will not hold up this process. I also wanted to thank folks who participated in the public comment period for the recently proposed rule changes for Chapter II of Section 21. We address all comments and questions with written responses, and we’re in that process right now. Thank you for submitting comments, we really value that feedback.

-It was asked once the emergency rule becomes effective, if providers will be able to retroactively bill. It was asked what kind of a format will the Department use for that.

**Emily:** I wish I could say, but those details will be made clear when the rule is provisionally accepted. There was a question from a provider looking to know what exactly the new rates are, and that’s not something I can share right now, in the rare case that there might be some last-minute alterations while in the internal review process.

**Waitlist Numbers as 8/31/17:** Section 21 – 1631: Priority 1 – 0; Priority 2 – 609; Priority 3 – 1022. Section 29 – 0.

**Emily:** Last month there was a request for us to report out on how many offers go out each month for Section 21. I believe in the minutes we stated that this is something we could provide. Upon further reflection, I’m unsure if we should report on that monthly; perhaps reporting on these figures quarterly would be more advantageous. Upon further reflection, we looked at our policy, and started to feel a bit like that was too narrow in terms of the small world we live in, where someone could see one Priority 1 offer going out in one month, and perhaps know who that person is. It could lead to misconceptions. We’re still open to providing that information in a larger timeframe in quarterly reports.

**Cullen:** When would we see the first quarterly update?

**Emily**: Next month we can provide July, August, and September data.

-It was asked when the Section 21 forum results would be available.

**Emily:** It will be very soon.

-At the last meeting, Karen had shared that the funding for the rate increases was for one year, and as such the Chapter III, rules changes for both Section 21 and Section 29 would stipulate the rate increase being in effect for one year. It was asked if the Department is anticipating another round of emergency rule changes in the next legislative session.

**Emily:** I’m sure people have seen similar rule changes in the past, where a rule is only written to be in effect for a limited period of time. My understanding, though OMS ([Office of MaineCare Services](http://www.maine.gov/dhhs/oms/)) would have final say, is the rates that are currently in effect, before the increase approved in the budget, would go back in place once that time period is over, which in this case is one year.

-It was asked if there was any news or information on the OIG (Office of Inspector General) Report.

**Emily:** If folks are reading the media, and the Portland Press Herald recently reported, that the Department received a list of questions recently from the HHS (Health and Human Services) Committee regarding the OIG Report. When we have those answers finalized, which will be any day now, they will go to the Committee and then be shared widely.

-It was asked what the Department’s next steps are in terms of any plans to implement the recommendations from the OIG Report.

**Emily:** The appendix to the report includes the Department’s response, which is not very detailed. The Department agreed with some of the findings, and agreed with some of the recommendations as well, and had already started to put some of the recommendations into effect. There’s still work to be done.

-It was stated that a lot of families have been asking about the respite contract. It was asked if the Department has an update on respite services.

**Emily:** Some folks might know that Section 29 now includes respite as a covered service. In the past respite was a component of our contract with ESM. This is not the case now, but funding for respite is still available. People can apply for the funding through their case managers, like with the family support fund.

**Cullen:** Thanks for being here, Emily, it’s very much appreciated!

**State Legislature Update: State Legislature is out of session.**

**Federal Update:**

**Cullen**: There’s not much to report as the State Legislature is out of session. However, a few months ago, DHHS had put forth a Section 1115 Waiver Application. This particular waiver effects folks who are considered to be “able-bodied,” but could be precedent-setting for all of Maine’s other waiver programs should it be approved. The application went through a state public comment period, and two public hearings were held. Some of the comments during this public comment period expressed concerns about people being able to access healthcare and services if this waiver should go through. The application has been formally submitted to CMS, and is now in a 30-day federal comment period, which ends at 11:00pm on 9/16. [Maine Equal Justice Partners](http://www.mejp.org/) (MEJP) is encouraging people to submit comments, and they’re willing to help. MEJP has information on the original proposal, comments received, changes made due to comments received, and the final application package sent to CMS. They are preparing to file a lawsuit, in the event that the application is approved; they will build their case based on the comments submitted to CMS.

**Lydia Paquette – Maine Association for Community Service Providers (MACSP):** [MACSP](http://meacsp.org/) will be submitting comments, and I’m happy to share that with members of the Coalition. We’re especially concerned about the penalty fee of $10 for using the Emergency Department (ED) and not being admitted. We’re concerned about rural areas that don’t have easy access to health clinics, where the hospital is the only option.

**Cullen:** There are a handful of other provisions in the waiver application that are concerning regarding people’s access to healthcare and services. There is a small window to weigh in. You can reach out to MEJP or Lydia for more information; let me know if I can help put you in touch with them.  *(To view the submitted application to CMS* [*click here*](https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/1115/downloads/me/me-mainecare-pa.pdf)*. To view and submit comments to CMS* [*click here*](https://public.medicaid.gov/connect.ti/public.comments/view?objectId=1892003)*.)*

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

**Lauren Wille:** I wanted to highlight two things. We’ve been participating in a Restorative Justice Coalition. Restorative justice is almost like a form of mediation between two parties who have had a conflict. We’re looking at applying these principles to people with ID/DD and a pilot project is currently in development. It remains to be seen what form that will take, but be on the lookout. The other thing I wanted to put out there is we have been getting a lot of calls about issues with transportation. It appears the issue is a disagreement between brokers and agencies regarding whose duty it is to provide transportation to work and community supports. We’re attempting to speak with the Department about this and getting clarity on the regulations.

**Other Business:**

* Specialized Housing, Inc. is holding an information session on Supported Housing with Home Ownership for the 14 E Street Project opening in February (3 spaces remain). The information session is on 9/27 at 7:00pm, at the South Portland Community Center, 21 Nelson Road. RSVP to Mary Chris Semrow to save a seat: mcsemrowshi@gmail.com

**Cullen:** Check out our website [www.maineparentcoalition.org](http://www.maineparentcoalition.org). You can find the title of any of our past presentations; Click the link, and you will go right to the minutes. There is also a forum on the Section 21 & 29 page on the website. You can log in and post questions/topics for other parents to answer. Additionally, the website can always use more pictures. Check out the recently updated Service Timeline. Our goal is to be an easily accessible information clearinghouse.

The next meeting will be on **October 16, 2017**

***\*\*\* Please note the next meeting is the 3rd Monday of the month due to the holiday\*\*\****

**Featured Speakers: Skip MacGowan. Topic: A continuation of the review of the history of the system of care for people with intellectual/developmental disabilities, including Pineland, the Consent Decree, the Consumer Advisory Board, and the mechanisms put in place to ensure the system of care worked well.**

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).***