October 16, 2017

Minutes

Present: Kim Humphrey, Jenn Brooking, Luann Lawlor, Rob Lawlor, Misty Niman, Frances Ryan, Jamie Whitehouse, LaRene Wentworth, Nonny Soifer, Betsy Mahoney, Glenda Wilson, Catherine Krupsky, Julie Brennan, Peter Stuckey, Ed & Suellen Doggett, Arthur P. Clum, Patrick Moore, Beth MyLroie, John Regan, Sanchia Snyder, Sue Murphy, Megan Meehan, Sahri Chapman, Debbie Dionne, David Cowing, Julia Brown, Staci Converse, Margaret Cardoza, Nancy Gavel, Katlyn Blackstone, Mimi Edmunds, Rachel Dyer, Skip MacGowan, Tyler Ingalls, Charlene Kinnelly, Cullen Ryan, and Vickey Rand. Via Zoom – Bangor (UCPofME): Elizabeth Whitmore. Winthrop (Autism Society of Maine): Cathy Dionne, Lydia Dawson, Cheryl Stalilonis, and Darla Chafin. Sanford (Waban): Brenda Smith. Auburn (John F. Murphy Homes): Ann Bentley. Brunswick (Independence Association): Ray Nagel and Colleen Gilliam. Waterville (Waterville Public Library): Pam Cairnie. Camden (Coastal Opportunities): Hillary Steinau, Linda, and Cindy. Farmington (LEAP): Kristin McPherson. Presque Isle (Central Aroostook Association): Steve Richard. Misc. sites: Stacy Lamontagne, Romy Spitz (with interpreters), and Bonnie-Jean Brooks.

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

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**Cullen:** I didn’t hear anyone introduce themselves from DHHS ([The Department of Health and Human Services](http://www.maine.gov/dhhs/)), so it doesn’t appear we have anyone representing the Department at the meeting today. Is that right? Hopefully we’ll be joined by DHHS from a remote site as the meeting progresses.

I wanted to add, this Friday, the Health and Human Services (HHS) Committee is holding a hearing to potentially confirm Ricker Hamilton as the new DHHS Commissioner, a role he has been fulfilling in an acting capacity for the past few months. This is a public hearing, and it presents an opportunity to thank Ricker for his participation in this Coalition and for DHHS’s efforts to expedite the doubled Section 29 cap, and rate increase. By participating you might have a brief dialogue with the HHS Committee and the potential new Commissioner about what is and is not working, raise questions, and make suggestions about what could be improved, such that they could be addressed by an incoming Commissioner. *(Public Hearing Information: Friday, October 20th at 9:00am in front of the HHS Committee, Cross Office Building, Room 209)*. This is an opportunity to talk about the needs of people with intellectual/developmental disabilities, and to ensure that the needs of these vulnerable populations are front and center. Another opportunity such as this is unlikely to occur for a while, so I encourage you to participate.

**Peter Stuckey:** They have framed this as a hearing about Mr. Hamilton. If you stray too far from that topic, you may get cut off. If you could frame what you’re going to say as a question or comment about how it relates to what the Committee should be looking for in a new commissioner, it would be advantageous.

-It was asked if emailing questions or comments to Committee members ahead of time is a good strategy.

**Peter:** That would be ideal, because the Committee members could address those issues directly with Mr. Hamilton. If you hear testimony throughout the hearing and it raises questions or comments, you can always write them down and give them to the clerks to disseminate to Committee members.

**Featured speaker: Skip MacGowan. Topic: Part two of the history of the system of care for people with intellectual/developmental disabilities, including Pineland, the Consent Decree, the Consumer Advisory Board, Community Standards, and other mechanisms put in place to ensure the system of care worked well.** *(*[*Click here for an audio recording of the meeting, including the featured speaker/presentation, and other related/referenced materials*](http://www.maineparentcoalition.org/october-2017-presentation.html)*)*

**Cullen:** Today’s presentation is part-two of a multi-part series on the history of the whole service system and how we got to where we are today. Reading the minutes from the last meeting, it was a powerful history to hear, but it was a powerful history to read as well. This is a neat opportunity to capture some unique history. There are parallels to what happened in the past to what’s happening now, and that’s concerning. It’s important for us to be aware of the history as we work collectively to make the current system work, and work well.

**Skip MacGowan:** At last month’s meeting we covered 65 years of history. It was all awful. It was appalling. Believe me, I just gave the soft overview; there are much darker parts of it too.

When we concluded the last presentation, Peter Bowman had become Superintendent; he was in that position from 1953 to 1971. This was a period of change at Pineland. The medical model took over. Staff wore white uniforms. But, all of the problems continued. Bowman did a few things that were fascinating. He came right out and said they were running on slave labor, that higher functioning patients – yes, they were called patients due to the medical model – were caring for lower functioning patients. Bowman felt this was the only way they could come close to providing any level of adequate care. I’m not sure how I feel about that. However, he did start talking publicly about the need to make changes at Pineland. Despite changes, things were still very bad. The nomenclature at the time were “incurables,” “trainables,” and “educables.” Approximately 40% of the population at Pineland at the time, according to its administration at least, were determined to be “incurables,” who could not care for themselves. So, half the population was cared for by the other half. There was a general attitude that “incurables” were space-takers and just needed custodial care. There wasn’t much of an attitude that they could be helped. It was appalling. Bowman was clear about it being appalling. To his credit, honesty is all we can ask for; at least we knew what we were dealing with. His vision was for the “educables” to be in the community and working. However, I’m not sure that was a significant improvement for anyone. First, they were only paid $15 per week, the majority of which went to their Pineland savings accounts. Even in the 1960’s, I’m not sure $15 per week was a fair wage; I’m pretty sure it wasn’t. Work placements included egg farms, farms of all types, many females were placed in nursing homes or as live-in maids. Bowman couldn’t place too many people out in the community because he had to keep that delicate balance of having higher functioning people care for people who couldn’t care for themselves.

During Bowman’s tenure, Pineland Parents and Friends was created – we touched on this a little at the last meeting. At the same time, the National Association for Retarded Children, had been talking about alternative solutions to institutionalization, and Maine had a chapter: The Maine Association for Retarded Children (MARC). I’ll simply tell you what I know. My understanding was Pineland Parents and Friends solely consisted of family and friends of children at Pineland. MARC, on the other hand, was comprised of the parents and family members who said no when doctors said the best thing was to place their children at Pineland. These were people who tried to do it on their own. MARC members started many of the agencies represented around the table today. They started schools before there was special education. They created services that were delivered out of church basements. At the time, MARC was providing the only community services in Maine.

Bowman instituted a practice that later became beneficial to the system at large – when people were placed out of Pineland, they ensured that there was someone who visited them in the community – usually once per year. When people were placed out, either on temporary status or permanent status, they were still on the rolls at Pineland; it was like a long yo-yo string that could be pulled back at any time. If people didn’t live up to the expectations of those they were serving, they could be pulled back to Pineland. From the mid-to-late 1960’s, about 600 people were on temporary or permanent status, this represented a little over half of the population at Pineland – it was a substantial group. Because Pineland had placed them, Pineland had visiting social service staff, presumably at least yearly, to ensure everything was all right. Everything wasn’t, but that’s the way it was.

MARC and Pineland Parents and Friends didn’t agree on many things. Pineland Parents and Friends could be critical and demanding, but they were not sufficiently critical and demanding; they were cooperative but they did a lot of good. It’s remarkable the amount of work they did for Pineland, but it wasn’t sufficient. In 1969, the *Maine Times* released an exposé on Pineland, a series of articles penned by reporter Hannah Kamber. This marked the first major step in producing profound changes at Pineland. The exposé included photographs, which depicted the appalling conditions at Pineland, including pictures of people tied to radiators, sitting in fetal positions, and other appalling images reminiscent of [*Christmas in Purgatory*](http://www.disabilitymuseum.org/dhm/lib/catcard.html?id=1782), which we touched on at the last meeting. This exposé was a catalyst which got people thinking and talking. The media played a vital role. People started to say that something was very wrong with the system. Throughout this time, Bowman increased efforts to place people out of Pineland. To his credit, Bowman said people who are placed out should have a system to enter, decent living environments, and so on. However, Pineland Parents and Friends and the public at large were appalled with the *Maine Times* exposé, and discussions about the need for profound change began in earnest – and changes were in fact made.

Peter Bowman had great supporters and great enemies. He was previously a powerhouse in the South, with almost unfettered power. He brought in a lot of money, and according to him Pineland was in the black financially. Though, how could it not be when it operated based on systemic involuntary servitude? Bowman really wanted to do something noble, he wanted Pineland to be a diagnostic and research facility to address the underlying causes of ID/DD, but this was not possible given the population at Pineland and its resources. By the mid to late 1960’s, Bowman was a marked man, people were out to get him, saying he had too much power, and his vision was honorable, but it wasn’t his mission, nor was it the way in which Pineland operated. After the exposé, there were some changes. The exposé detailed a training program, which was run by Albert (Andy) Anderson, a psychologist, in which people considered to be very low-functioning, the “incurables,” were trained on basic skills such as dressing, eating, and using the bathroom. In Anderson’s program, people were cared for and treated like human beings, regardless of their level of cognitive or behavioral functioning. He did well. He was using basic behaviorism, rewarding people for doing basic, self-care tasks, and people learned things, though it was a limited number of people. Of course, people can learn if you give them the opportunity and resources to do so. Anderson started saying “a lot of these people don’t belong at Pineland.” He was among the first people to envision a world in which Pineland, and institutions in general, didn’t exist. This mentality scared Pineland Parents and Friends, because they had listened to doctors, who were supposed to be the experts, and under their advisement had placed their children at Pineland. If their children were placed out of Pineland where would they go? Pineland Parents and Friends knew what was going on in the community was also sorely lacking substance, and was at best volunteer work.

Bowman and Anderson had very different styles and ideologies, which caused great conflict. This conflict led to warring parties throughout the state. Anderson’s candor, and assertion that people didn’t need to be at Pineland, increased tensions with the state, elected officials, staff, and parents – which persisted well after he left Pineland. Things were bad. Anderson went on to leave Pineland and become the first Director of the Bureau of Mental Retardation (BMR), which was formed legislatively as a division of the Department of Mental Health and Corrections, and designed as an oversight body for Pineland.

Four years later, in the spring of 1972, there was a second exposé of Pineland, this time a series of articles penned by reporter John Kerry (who went on to become a representative) published in *Church World,* a weekly publication produced by the Catholic Church of Maine. This exposé documented the same conditions as the *Maine Times* exposé, including horrific photographs illustrating the appalling conditions. However, Kerry’s articles were more affirmative that things could be improved with the right resources, staffing, and community services – people could live better lives. Everyone agreed with him then, just as everyone agrees with this now. Though, without an injection of resources and substantive changes, conditions wouldn’t improve. It’s costs money. What this always comes down to is the ability to pay the money to do the job. Let’s stop for a minute, now. Things *can* change. And when I say they, I mean us; it was our institution. We have a government by and for the people. There was something about the late 1960’s, where people truly believed that; maybe people still believe it. There were a lot of attempts to start pushing the system in different directions. The directions were varied, and sometimes senseless, but there was movement and discussion. Just talking about it, doing *something* is positive movement. After Kerry’s exposé, there were changes. The Legislature was taking it much more seriously; they admitted things were bad. Blame was passed around – it was Bowman’s fault, or Andy Anderson’s fault, and so on. In reality, it’s our fault; then and today. A lot of parents didn’t want to be blamed. The exposés provided a picture of Pineland, a peak behind the curtain, to which people often weren’t privy. By the late 1960’s, people could go into the units. The units were appalling; literally appalling. Chicken wires separated the sleeping quarters from the day quarters. The yards had chicken wire cages, in which residents were allowed to sit. Given the staffing, I don’t know how it worked; I don’t know how it didn’t just implode. It was very bad. The compassion of the clients who cared for other clients is just beyond reason. Without them, people would have died in droves, even with them it was awful but they tried, and that is to be commended.

After the Kerry articles, there was a push by administrators at Pineland, and other institutions across the nation, to make changes to appease people. One of the things they did was convert a direct care provider position into an advocate. This was done by the institution, it wasn’t forced on them. Concurrently, nationally people began saying that people are trainable, people can improve with training. Anderson was a follower and practitioner of ideologies heralded by [Wolf Wolfensberger](https://actionctr.org/resources/profiles-in-courage/wolf-wolfensberger/), the originator of Social Role Valorization and the Normalization Principle. Wolfensberger was talking about normalization and deinstitutionalization. [He authored numerous books, with his most notable works being *Changing Patterns in Residential Services for the Mentally Retarded* (1969), and *The Principle of Normalization in Human Services* (1972)]. Take the time to read his work; it stands up today. The theory was, if you put people in normal situations they would behave more normally. It’s not about them, it’s about their situation. Pineland wasn’t normal. What can you expect to get out of an abnormal, unpleasant situation? These discussions were occurring, and parents were hearing about it. Parents had the same concerns, they believed Bowman when he said things were bad, they saw the exposés, but they were still left wondering: If not Pineland, where? They still had every right to say, “hey, you’re asking us to take a huge leap. To push them out the door and *maybe* there’s someone there to take care of them.” Even then, there was a desire to build a system. Parents were saying that their children would remain at Pineland until there were places for their children to go. They all wanted someplace to go to, and it wasn’t happening. All this costs money that was hard to come by. The Bureau of Mental Retardation (BMR) was comprised of only three people. I’m not sure they provided much in the way of services; they would have tried, I’m sure, they were decent people, but it just wasn’t happening.

A woman named Alison Anspach was the first advocate at Pineland. She graduated from law school and was at Pineland about a month later. She arrived at Pineland and started complaining about the conditions. She was good. She represented a change agent who didn’t care who got hurt, not the clients, but she wasn’t looking at staffing and going “well there’s a lot of jobs here, we have to keep the jobs.” Her focus was on the individuals, saying, “do better for this person, he needs x, y, and z.” And she got a lot of it, on a case by case basis; but it was one at a time. This was one person negotiating with a huge bureaucracy. Within the first year she was hired she started talking to Neville Woodruff, a lawyer with Legal Services Corporation (now known as Pine Tree Legal). Institutional reform was happening all around the country, including New York and Massachusetts, which were both being sued based on appalling conditions, lack of services, people not being free but not being treated – essentially warehousing people in institutions. This was not acceptable. Neville went to Pineland and spent time there. Not more than eight or nine months after Alison had first contacted him, Neville started drafting the initial complaint. In reading the complaint I learned that one should not read reams and reams of legal documents – they are quite disturbing. What I don’t understand, is how someone like Neville who had no background in this field, could learn a system, all the moving parts of institutions and care, and condense it down into a mere 18-page complaint. Somehow, in 18 pages, Neville managed to capture at least the high points of what was wrong with Pineland. He had eight areas of inadequacy, in which drastic improvement was needed; one of which was the environment – that was easy. It was unclean and barren, to put it extremely mildly. Neville took normalization to heart early on in his work. He began saying that at the very least there was a need to place people out of Pineland who didn’t belong there. Well, no one needed to be there; it was awful! Neville never said, ‘okay we’re going to make Pineland good enough so people don’t have to leave;’ he knew from the start that was not going to happen. With the ideology of normalization in mind, how would one normalize what I described last month? Where would one even begin? Let’s clean up the feces first? Where does that end? The idea is preposterous. On July 3rd, 1975, Neville filed this 18-page complaint, which stated the environment at Pineland was appalling, people don’t have freedom, they don’t get exercise, and they don’t receive treatment. Additionally, Neville stated that previous reports regarding Pineland were not particularly accurate, but any negative findings were certainly accurate. There were 66 people receiving educational services, which may seem positive; however, it’s not as positive when you consider there were 780 people there at the time. Reports often focused on the positives. Neville pointed out people would benefit from training. Neville’s complaint was predicated on cruel and unusual punishment, state law to inflict harm, and so on; things that had been acceptable and accepted in institutions being violations of people’s civil rights.

Peter Bowman was escorted off the Pineland grounds at the end of 1971. There was a real push and pull between Bowman, the executive branch, and the Legislature, which inevitably resulted in a Governor who said this was not acceptable. At almost the same time Jim Longley was elected Governor, Bowman was ousted. When Peter Bowman left, Conrad Wurtz became the next superintendent. Prior to Wurtz, Pineland had many acting superintendents, including Charlene. How much authority does someone in an acting capacity have? Not much. They did the best they could. They, like everyone else, wanted things to change. The notion that a court case had been filed to bring resources and change to Pineland was a big deal, and Pineland staff supported it with reservations, as you might expect because essentially it was a lawsuit against them. However, there was a real recognition that this was long overdue. I believe it was Andy Anderson who first said that he relished the day that someone figured out that they should be suing Pineland.

There was a period of negotiation between the State and Neville. Neville’s case attracted national attention, and the assistance of the Mental Health Law Project out of Washington (now known as the [Bazelon Center for Mental Health Law](http://www.bazelon.org/)). Neville’s suit was the first lawsuit in the country approaching institutional change and the community, encompassing people on Pineland’s rolls *as well as in the community*. If he had just gone after the community, there would have been no grounds to file the suit. The removal of people’s liberty without giving them treatment in return, is a strong constitutional issue. In the community, people’s liberties hadn’t *technically* been revoked, at least in the legal sense. When they became less lucrative, many of the chicken farms cleared out the chicken coups and turned them into boarding homes. Caring for people out of Pineland became lucrative, and though I’m sure there were some places where they did a passable job, the “care” was merely warehousing people. They were neither equipped nor funded to provide adequate care. Because Neville sued on behalf of the population at Pineland *and* the 660 people in the community, the case was a very big deal – that community link was quite unique and as such attracted national attention and the involvement of the Mental Health Law Project. Everyone I’m talking about was so bright and insightful that it frightens me. In retrospect, I’m not sure how they knew how to do what they did. These are people who had a vision 20-years down the road. It’s truly brilliant. Neville developed Appendix A, the institution standards, and Appendix B, the community standards. How do you develop something like that? If we met the criterion in Appendix B today we’d be better off. To this day we’re still not meeting the standards – things like annual dental screenings, and so on.

In that three-year interim, between the initial filing and the settlement, Conrad Wurtz left and George Zitnay became superintendent. Zitnay is the name attached to the consent decree, known formally as Wuori v. Zitnay (originally Wuori v. Bruns, after Margaret Bruns, the acting superintendent at the time of the initial filing). It’s ironic that Zitnay is the name that became attached to the case, because Zitnay was a charismatic dreamer, a wonderful person in many ways, and he was exactly what Pineland needed. He came in and he was extremely focused on normalization and community development. He told the truth; that’s the most you can ask for from people in systems when the truth is not plentiful. Zitnay said it was bad, but it could be improved. And he did it. He cleaned up wards, hired staff, and convinced the Legislature that it was well-worth the effort to do things right. The parent groups became vibrant and started making demands. Suddenly, parents were hearing that their children didn’t have to be at Pineland and could do better elsewhere. George said it over and over: With adequate resources people could be in the community, be close to home, have friends, have real jobs, socialize – they could have real lives. There was a spilt down the middle, with some parents saying this would be great, and others saying that they were told Pineland was the best by all the professionals and that they wanted the best for their children. Many believed, even after the exposés, that George Zitnay could improve Pineland sufficiently. George tried to make changes and improve Pineland, and he did over his tenure; Pineland got noticeably better. It didn’t smell, people were clean, and people were clothed. It wasn’t as good as it should have been, but it was better than it was.

-There was a comment that how it was done, specifically referring to bathing, matters. It wasn’t done well, nor would the “bathing” that occurred be considered humane today.

**Skip**: You’re right, they were nowhere near perfect.

**Skip:** The lawsuit never went to trial. Everyone was preparing to go to trial, and most are fairly sure it would have been a successful case. This is one of the primary reasons the state wanted to settle; if this had gone to trial it would’ve been a nightmare for the state. Neville, because of his status as a complainant, could delve into the reality of Pineland. It would’ve been an embarrassment if everything came to light, so the state decided it would negotiate. Three years after the initial complaint the state settled; there had never been an evidentiary hearing. This means nothing was on record other than an agreement from the State saying, “you said things are bad, we agree to fix it.” Due to this, there was never a body of evidence to point back to.

In July of 1978, Judge Gignoux approved the consent decree. At this point in time, David Gregory, a law professor at the University of Maine, came in to serve as the first court master. He was an interesting character. He was very laser-like in his vision. Everything outlined in both Appendix A and Appendix B was supposed to be completed in two years. I don’t even think it was possible to accomplish everything in that timeframe, but it was definitely not plausible. However, judges want time frames. Whoever examined those documents and thought it would take about two years to complete – well I don’t know what they were thinking. During those first two years, David spent a tremendous amount of time looking at the details of the lives of the individuals at Pineland and picking apart everything, pointing to it, and saying it wasn’t adequate. He was brutal. He was unrelentingly honest, saying things like “you promised the court something and you’re not living up to it.” He thrashed on everyone in sight, even people supporting the decree. It was of little consequence to him what side they were on, if they didn’t get the job done he would say they didn’t get the job done. It was that simple. He as one of the most fascinating people I have ever met. Until the day he died, I considered him a resource on whom I could depend to be clear and direct about how it should be done and in what timeframe. He will go down in history across the country as one of the most activist court masters ever.

Unfortunately, when someone takes this approach, it results in a strange dynamic between all parties involved – the staff, legislators, and the executive branch – because you have these people on the other side of the table, people who wanted to get it done and were working under implausible timeframes to do so. Legislators would say, “why should we give you this money? You haven’t accomplished the task!” David wouldn’t say “they’re trying.” He was prone to threatening people, whatever it took. Unfortunately, when you have legislators saying we’ve given you millions of dollars and staff to do this, and David then says it’s still bad, it’s not conducive to receiving the funding so desperately needed to satisfy the consent decree. David was right, but politically one might want to soft-peddle that when asking for more money. The administration in power at the time appreciated what David was doing, but it was killing the Legislature and Governor’s office. If you don’t say what has been done well, what is working, even if there’s more to do, it creates a no-win scenario. David Gregory wrote reports to the presiding judge stating that a two-year timeframe was ludicrous, and that they couldn’t accomplish it in 100 years. He was talking about people who truly cared. At the end of close to four years it was determined that all the negativity David was pumping into the Legislature wasn’t helping. Is that true? I don’t know. Honesty seems to be the best policy. Though, I understand in a political world there’s a balance; you can demand more, but you also must give credit where it’s due or the heavy lifters won’t do the lifting. It’s like blaming the providers for the problems in our current system. Don’t blame the people doing the heavy lifting – help them! If you criticize the people doing the job, then maybe the job will stop. So, after the four years of David Gregory’s “do more, you’re not doing enough” staunch stance, the state moved to remove him as court master. The plaintiff could have said, “absolutely not, he’s telling the truth,” but he didn’t. I remember debating with Neville about this, but he was looking long-term: Momentum needed to continue, and if you discouraged the administration, staff, and Legislature from doing the job, they wouldn’t do it, they’d disappear and you’d have to get someone else, with the likelihood that they wouldn’t have the vigor or the insight of the people who were already there, people who truly cared. This would include people like Zitnay, Kevin Concannon, Ron Welch, and Kevin Baack. A host of people who were dedicated to making a better system, were all getting kind of blackened by these reports. So, there was a motion to remove David Gregory, negotiations occurred, and ultimately, he resigned. David was replaced by Lincoln Clark, the second court master. Lincoln Clark was … he was not Neville.

Let me tell you a little bit about Neville. Neville got angry about this. He didn’t just present a case – he got angry and showed the anger, and demanded that people acknowledge they were doing a lousy job. After negotiations, he’d be on the courthouse steps saying, “it’s appalling that we’ve done this for three years and it hasn’t gotten that much better. It’s gotten better, just not enough.” He was a great cheerleader. Not having seen an evidentiary hearing, I don’t know how he would have been in a court room. I suspect he was great enough to be *pretty good*. He was certainly good on the public stage. He certainly pushed it every chance he got. He knew enough to keep it in the press. He did remarkable things. Neville argued that David was great, and I think he truly believed that, but he said it would not work long-term. He said, “we can fight for our principles or our realities, and the reality is we need the administrators, executive, and Legislature to do this job in a way that is meaningful and will hold.”

So, David left. Well, he never really left, he was just off the stage, off to the side. As I said, until the day he died I could go to him and get sane, clear advice on what to do, so I give him credit for that. Lincoln Clark was a totally different beast. He was much more attuned to the give-and-take of politics. He understood that you get more flies with honey than with vinegar. He was quick to tell people they’re doing a superb job of making these changes, of building these services in the community, of developing other options, of supporting startups. Most of the startups, most of the agencies represented in this room, started with a group of parents getting together and saying, “let’s do our own home,” and with somebody like Kevin or Ron Welch coming to a meeting and saying, “we’ll support you. What do you need? Can you get yourself incorporated, hire somebody, and get a home? We’ll get you the money; we’ll fund it.” Lincoln was very good at saying, “look at how far we’ve come in just five years!” His first report was glowing about what had been done. He wasn’t as good about saying what still had to be done. We all knew. Everyone knew, except the public. He was at least saying, “they’re headed in the right direction. This is possible. This is doable. Keep up the excellent work. Keep the funding flowing. We can do this!” David never came out and said we could accomplish what’s required in the Consent Decree, he kept saying we’re would keep fighting until it’s accomplished – but he never said it would be. From the beginning, Lincoln said, “I see, in the future, a real change, a betterment of our system. A community system that can serve all of the needs of all the people who need to be in the community.” It worked. At that time, the money kept following, and that was the most important thing. The Legislature kept believing. There was something about not having a guy pointing to the Legislature and making threats that made it a little nicer for them. They could feel like they were really going to do this. And, Lincoln was remarkable at saying, “we’re doing so well, and if you only keep supporting us we can do this!” There’s much to be said for that.

Now I can start a timeline. I’m sorry about this, but I have to do this because you wanted history, and history falls in timelines. I can do little a picaresque, stories about people, but it won’t give you the full picture. I’m not going to go into details on all the legalisms: The Complaint was filed, settlement, consent, judgement, appointment of court master, and from day one, David Gregory’s first report referred to the consent decree as a perpetual injunction. Now, I want to go back to Neville’s filing, because there were things about his filing that are important today. Neville’s filing basically said that there wasn’t enough money on Earth to reimburse these people for what they suffered. He said they wanted injunctive relief; they wanted change. They wanted guarantees that things would get better, and would never get bad again. In lieu of damages, they accepted injunctive relief. That’s a remarkable thing, and I’ll tell you why that’s a remarkable thing. For instance, bed sores in a nursing home. If you go to a nursing home you’re presumed to get appropriate care. If you get a bed sore you can sue for lack of adequate care. You’re not supposed to get bed sores if you’re cared for adequately. The judgements for people who get severe bed sores are in the millions. The average damages on those suits that aren’t settled, they’re usually settled quickly, but the ones that aren’t range from $800,000 to $16 million in the case of a man who died because his bed sores became infected. $16 million – most of it punitive. Try thinking about 1,600 people and the things that they could sue for; bed sores seem minor compared to being abused, neglected, tied to radiators. It’s appalling. Neville said, “you can’t pay them, we want injunctive relief.” And, that was what the decree was. Neville pretty much said they didn’t want money, they wanted permanent change.

David Gregory, in his first report, said the decree is a perpetual injunction. Perpetual: To go on forever. Unless changed by a court. Now that, that becomes very important later. David Gregory’s report went to a court. He reported to Judge Gignoux, who released the report. That simple transfer of information, from David Gregory up the line to a judge, then down the line from the judge, indicated that if David said it, and the judge bought it and released it, he agreed. So, we can presume that the perpetual injunction language was agreed upon by Judge Gignoux. This wasn’t just fix it for the day, this was fix it forever, and don’t let it happen ever again. The other thing about the consent decree was that it was designed to be *minimum* acceptable standards. *Minimum*. Not, “this is perfect, this is what everyone should have.” This was the very minimum that’s acceptable to the federal court; the bare minimum to ensure people’s rights were not violated. I can tell you as of this day, full compliance with the original decree has never occurred. *Never occurred*. And still hasn’t. That’s appalling, when you think how long it’s been and how much money has been spent. Full compliance has never occurred.

It went on, and things got better. Pineland was never somewhere I would sign up to live. No one was going to say, “oh gee, two weeks of lovely, downtown Pineland, is something I want.” But, it was clean, and it was staffed. To give an example of how things had changed, two years before I started at Pineland the total staff compliment was about 180 for 1200 people. That’s to cover three shifts a day, and you have to exclude all the doctors, nurses, maintenance, grounds crew, cooks, custodians, fire department, and security. You have to remove them from the 180 to get the number of people who actually provided care. That’s unbelievable, and obviously wasn’t working. By 1981, Lincoln Clark basically said that they had maxed out Pineland, it’s as good as it’s going to get. That’s not saying much because it still wasn’t very good. Institutions aren’t good, but it was as good as institutions get. It truly was. I think most people were proud of it as an institution. It’s kind of an oxymoron, but we’ll leave it there. By 1981, Lincoln said they had done all they could do and the focus must be on the community, the staff compliment was something like 875 staff and 620 clients, and the vast majority of the staff were in fact direct care staff. So, things had changed, it was better; no one was denying that things were better. There was new furniture, they gutted, cleaned, and fumigated buildings, and rebuilt the inside so it was more home-like. There were individual and two-person bedrooms, and a communal area. It got better. As institutions go, it was probably a good one, I don’t know. Saying “good institution,” on its surface seems like another oxymoron.

Lincoln’s focus in 1981 was discharging Pineland and turning the attention to the community. Which happened. This doesn’t mean that anything about Pineland was forgotten – now it had to be maintained. Most of that maintenance were things that went on every day. They had to keep treating people, evaluate their needs, develop individual plans to meet their needs as individuals, plan for what it would take to get people to the point where they can live in the community. I think everybody agrees that if you have your choice, you would rather live in the community than in an institution. From 1981 to 1983, the total focus was on the community, and the development of community options. Now, there had been community options. From day one, Pineland was required to develop something like 64 beds every six months until the needs of the whole class were met. They didn’t do it, they came close. The new developments were good developments. I think the problem in the community was what was there to begin with had to be swept aside. Someone had to go into those chicken coups and say this is not what we want for services in the community; this is not adequate. Those three years were focused almost exclusively, from the court master’s perspective, on getting the community stable. There was a flurry of development, and there was a kind of “we’ll try anything that people think will help” attitude. Families would come in and say, “we just want a home in downtown Lewiston, can you help us?” And the response was yes. The money flowed, placements occurred, and people were moving out of Pineland. There was a total attitude shift; no one at Pineland dared to openly say, “this person is incurable, there’s no sense in trying.” That whole notion was yanked away from people.

Speaking of the community, Public Law 94-142, The Education for All Handicapped Children Act, enacted in 1975, had a remarkable effect on the community. I don’t know about you, but I remember the first year of school, there were a couple of kids in the class who were “different.” Sometimes they would act out, the teachers would panic, and someone would come remove them from the classroom. By the end of that year, those “different people” disappeared. That’s because schools determined those kids were disruptive and they wouldn’t permit them to attend school. They could just say that. That’s another reason for Pineland, right? Parents started saying, “what are we supposed to do if our child doesn’t go to school? How do we get services?” That changed with 94-142, which declared that the system had to find a way to make education for everyone in the community work. It didn’t always work, it still doesn’t always work, but it’s there and no one can say someone is too troublesome to go to school. That’s a pretty amazing thing, when the Legislature and the courts say this is how it’s going to be from today on. It changed everything, and what we have today is a society that’s used to having a range of people with disabilities out there doing their thing, and they accept it. That’s the biggest change I think, bigger than the consent decree, that the public has become accustomed to everyone being part of the game. It isn’t ideal yet. Community integration is still a work in progress, normalization still needs to be taught and practiced, but acceptance has blossomed. Most people recognize that it’s good that everybody participates. President Kennedy, when he was talking about the need to deal with people with disabilities in a positive way, his famous “quote” *(it’s often attributed to President Kennedy, but he borrowed it from another source)* “a rising tide raises all vessels, from the lowliest point to the most luxurious yacht.” There’s something so wonderful about that vision. It works; it worked.

Now, I think what we’re required to do is set the floor. Remember the “minimum requirements,” aspect of the decree? I think we all must start saying we’re going to set the floor for what we think is minimum, in terms of treatment of people who have needs. As a society, that’s what we must do. It’s not “them.” It’s not we want them to change their mind. It’s us. We need to do this. We own it. Anything that’s wrong belongs to us, and if we want to change it, it’s up to us to do so. The healthcare discussion that rages around us, it’s like a battlefield. Well, it’s about this population as much as it’s about you and me. We should be saying what’s acceptable as a society. What’s the bottom line? What’s the minimal acceptable standards that *we* adhere to? Then, we should require our representatives to present those, to live with those. It’s doable. It was doable in the 1960’s; it’s doable now. It’s up to us to do it.

**Discussion:**

-It was stated that there was a period in which the system was bifurcated – if people had ever been at Pineland there was a certain amount of money that would follow them. Whereas, people who had never been in Pineland had decreased prospects in this regard. It was asked when this occurred.

**Skip:** The period of development, from 1981 to 1983, was focused on the community standards. Parents started saying, “wait a minute! We did this all on our own, we never sent our kids to Pineland. Why are we being excluded?” By the end of the first year, and to some degree Lincoln Clark is to be credited with this, there was the realization that this didn’t seem fair. The Department wholeheartedly agreed with these parents. These were people who wanted good systems. So, for every placement from Pineland there would be a development in the community for a community member. By 1985, this practice was ensconced. It was the only fair thing to do; the equities in this were obvious. Families that suffered for years caring for their children shouldn’t be punished, and the Legislature agreed.

There was a tipping point in the 1990’s. Previously, people had discovered that Pineland was a money-generator; it generated a lot of money, which was recirculated back into the community. In the 1990’s, this changed. Pineland was expensive, it was not generating money, and it was difficult to make the argument that it was “so good” it should be kept operational. It had improved drastically, but we were *so* close, people began saying, “why don’t we do it all in the community?” I have a lot to say about closing an institution when community services weren’t lined up. From 1991 to 1995, people were saying, “sorry we can’t serve you because we’re closing Pineland.” That was a real issue. I’ll get to this issue more in part three of this presentation next month. They did try though. And the Legislature, bless them! They were getting a constant bombardment of, “we need more!” The Legislature was great. We were building a system that required documentation. The system started to be able to generate specific information about individuals and their specific needs, which could then be brought to the Legislature to clearly document specific needs. The Legislature listened, and did the right thing. They didn’t balk at all. They built community services for the community because it was right, not because it was required. That’s amazing. The [Maine Developmental Services Oversight and Advisory Board](http://mainedsoab.org/) (known simply as the OAB), is the successor of the Consumer Advisory Board (CAB), which was established to ensure oversight of the Department to ensure this never happened again. If the OAB could complete its duties, with the information needed from the Department to do so, the system might work better.

**Bonnie-Jean Brooks:** I’m glad you mentioned the CAB and OAB. When I was chair of the CAB, we got a lot of specific information from the Department. We knew what the unmet needs were, we knew how frequently case managers were visiting clients, we knew how many open reports there were with Adult Protective Services (APS), and the status of those reports. This helped us to keep the Department’s feet to the fire; to hold them accountable. This is a very serious consequence of what’s going on now.

**Skip**: The Legislature is aware, but we need them to act on this. Someone must have a foot inside, to be able to look at things. I’m a huge fan of confidentiality, but there needs to be a portal into the system, someone must be able to look inside. This was the vision. Next month we’ll discuss what the CAB did when all these big players we’ve talked about stepped off the stage.

-A self-advocate stated that while she was at Pineland she was labeled “uneducable.” Today, she has a Master’s Degree in Education, but Pineland considered her “uneducable.” She stated that she appreciates it being stated that all people are educable. She continued by stating that we need to keep remembering this history. Liberty is the key word. The biggest danger to liberty is when people “mean well.” She stated that when people talk *for* others it doesn’t work; it’s wrong. When people talk *with* others, it works. She stated that in this pursuit to remember and document what has occurred in the past we ought to keep this in mind. She stated that not too long ago she was denied the ability to get married. It took an enormous amount of “proof” that she could in fact make the decision of her own accord to marry, so even today these issues still exist.

**Skip:** What I wish for the future is that we hear and document your story and the stories of others who lived this. Me telling the story isn’t nearly as important as individuals and families with direct lived experience telling their stories. The current administration doesn’t remember the history, and this is a problem.

-It was stated that one of the most significant changes, included in 94-142, was the mandate that parents have a seat at the table and make decisions along with others about their children.

**Cullen:** We’re only part-way through this series. We will continue next month with part three of Skip’s presentation. Skip, thank you very much for a wonderful presentation, yet again.

[Related materials to the presentation: [Appendix B, Community Standards](http://www.maineparentcoalition.org/uploads/2/6/1/1/26115022/community_standards_1978.pdf); [Skip’s Affidavit](http://www.maineparentcoalition.org/uploads/2/6/1/1/26115022/skip_macgowan_affidavit.pdf); and [a scanned version of the booklet Charlene passed around at last month’s meeting entitled *Summaries of Laws relating to the Commitment and Care of the Feeble-Minded in Maine*](http://www.maineparentcoalition.org/uploads/2/6/1/1/26115022/summaries_of_laws_relating_to_the_commitment_and_care_of_the_feeble-minded_in_maine.pdf)].

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

**DHHS Updates:**

**Cullen:** It doesn’t appear that anyone is present from OADS or OCFS. (No one from DHHS was present at the meeting; no updates were provided).

**State Legislature Update:**

**Lydia Dawson – Maine Association for Community Service Providers (MACSP):** A committee is working on proposed draft legislation regarding shifting special education services for 3- to 5-year-olds from the [Department of Education (DOE), Child Development Services (CDS)](http://www.maine.gov/doe/cds/) to public school districts. I will send more information on this, but it’s important to follow this closely. The proposed legislation regarding this is still in draft form, but we’re discussing what’s needed for a transition to that school-based model. There are concerns about what that will look like, because early intervention and education are very important and this is a major change. MACSP is a voting member on that committee and I would love to be able to present community recommendations. Please email me with thoughts or questions for that committee ([Lydia.Dawson@meacsp.org](mailto:Lydia.Dawson@meacsp.org)).

Additionally, as you may know the Department utilized the emergency rule-making process for both Section 21 and Section 29. Functionally, that raised the rates for Section 21 and 29 for Direct Support Professional (DSP) related activities, raised the cap for community and work supports in Section 29, and added shared living as an option to Section 29. As a procedural aspect, because the Department used the emergency rule-making process, those rules were provisionally accepted immediately and went into effect on September 29th. The Department then released proposed rule changes for Section 21 and Section 29 for these same changes, which includes a public comment period, for permanent adoption. In reading the proposed rules, we have some concerns. The Legislature set aside funding to increase the reimbursement rates; in their calculations, they had the rates starting on October 1st. However, instead of starting the new rates on October 1st, the Department made the rate increases retroactive to July 1st. So, functionally, that means the increase in the rate for service is about 25% less than we thought it would be, because the same amount of funding is spread across twelve months instead of nine. Additionally, there is a sunset provision, so, if nothing happens in this legislative session to make these rates permanent, they will revert to the old rates.

With the inclusion of shared living in Section 29, there are also general concerns about people utilizing shared living and not having any funding left in the cap for any community supports. We’ll be watching this and providing data to the Department, as well as this group, about whether we’re seeing a reduction in community supports and activities. Also, the rates have been increased for Section 21, but the caps were not increased correspondingly. There is concern that a possible unintended consequence is that people will reach the cap on Section 21 utilizing fewer hours of services than before, because the cap wasn’t adjusted for the rate increase. Additionally, when the Department included shared living in Section 29 it removed employment supports from the cap. As far as I have been able to tell, employment supports appear completely uncapped in Section 29. However, on Section 21 employment supports are still capped. So, there are some consistency issues across Section 21 and Section 29.

**Cullen:** Do you know when the public hearings will be held, and when the public comment period concludes?

**Lydia:** I don’t have this information handy, but will be sure to get it for inclusion in the minutes.

*After the meeting Lydia forwarded the following information:*

* **Section 21, Chapter III** *(Major Substantive Rule Change, to address rate increases approved for FY 2018)*

Public hearing: 11/1/17 at 9:00am, at the Augusta Armory

Written comments due: 11/12/17 by 11:59pm [Click here to submit comments.](http://www.maine.gov/dhhs/oms/rules/rulemaking_comments.shtml?id=769183)

* **Section 29, Chapter II** *(Minor Technical Rule Change, addressing the increase to the Section 29 cap, added services, and services available but removed from the caps)*

Public hearing: 10/31/17, 2017 at 9:00 am, at the Augusta Civic Center

Written comments due: 11/10/17 by 11:59pm [Click here to submit comments.](http://www.maine.gov/dhhs/oms/rules/rulemaking_comments.shtml?id=768757)

* **Section 29, Chapter III** *(Major Substantive Rule Change, to address rate increases approved for FY 2018)*

Public hearing: 10/31/2017 at 1:00 pm, at the Augusta Civic Center

Written comments due: 11/10/17 by 11:59pm [Click here to submit comments.](http://www.maine.gov/dhhs/oms/rules/rulemaking_comments.shtml?id=768758)

**(**[***Click here for more information on the proposed rule changes, including how to submit written comments***](http://www.maineparentcoalition.org/proposed-rule-changes-october-2017.html)**)**

**Cullen:** It’s important to commend the Department – we heard that implementation could take up to six months, which was very concerning. We voiced these concerns clearly to the Department and staff managed to utilize the emergency rule making process and get them provisionally adopted in more like three months. It appears that people may have discovered some concerns and/or possible unintended consequences of certain provisions of the rule changes, on which we ought to focus. It’s important to weigh in so we can help the Department get this right.

**Lydia:** The retroactive rate increases are also proving problematic for providers. It’s a big issue. The way the Department is reimbursing providers, providers must give the state back all the money they’re received for those services, retrospectively to July, then the State reimburses providers the full amount at the increased rate. It’s estimated that it could take the state up to two months to reimburse providers. Providers also must wait for the go-ahead to begin billing at the higher rate. This could cause a financial burden large enough that providers may have to close their doors.

-It was asked if anyone had information on the proposed legislation which would reinstate the Office of Advocacy.

**Cullen:** I spoke with a Legislator today; it will have to be reviewed by the Legislative Council. The Legislator I spoke with also expressed concern about the OIG (Office of Inspector General) report. He felt it was alarming, and was very interested in establishing measures of accountability for the Department, whatever that might entail. He seemed concerned about getting the system to work well for vulnerable populations. In his opinion, the Department’s response to the report was not adequate. *(*[*Click here for more information on the OIG report*](http://www.maineparentcoalition.org/oig-report-information-august-2017.html)*).*

**Charlene Kinnelly:** Because it’s the second session, any request for a new bill does require Legislative Council review. The bill may not actually make it.

**Cullen:** This could certainly be a topic raised at the public hearing on Friday.

**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 **November 13, 2017**

**Featured Speakers: Skip MacGowan. Topic: Part three of the history of the system of care for people with intellectual/developmental disabilities, including Pineland, the Consent Decree, the Consumer Advisory Board, Community Standards, and other 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).***