November 13, 2017

Minutes

Present: Michael Chapman, Chip MacGowan, Nonny Soifer, Kim Humphrey, Rob Lawler, Luann Lawler, Debbie Dionne, David Cowing, Ed & Suellen Doggett, Staci Converse, Nell Brimmer, Jennifer Putnam, Glenda Wilson, Patrick Moore, Julie Brennan, Erin Rowan, Rebecca MacCallum, Mary Malcolm, Priscilla Dimitre, Emily Melo, Peter Stuckey, Mary Chris Semrow, Margaret Cardoza, Tammy Pike, Jerry Silbert, Cullen Ryan, and Vickey Rand. Via Zoom – Bangor (UCPofME): Elizabeth Whitmore and Andrew Cassidy. Winthrop (Autism Society of Maine): Cathy Dionne and Ann. Sanford (Waban): Brenda Smith. Auburn (John F. Murphy Homes): Ann Bentley. Brunswick (Independence Association): Ray Nagel and Colleen Gilliam. Camden (Coastal Opportunities): Hillary Steinau. Farmington (LEAP): Kristin McPherson. Presque Isle (Central Aroostook Association): Steve Richard. Misc. sites: Stacy Lamontagne and Romy Spitz (with interpreters).

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

*Thank you to Senscio Systems, who has very generously covered the cost of lunch for our 2017 meetings!* *For more information on Senscio Systems you can visit their* [*website*](http://www.sensciosystems.com/)*, or connect with them on* [*Facebook*](https://www.facebook.com/senscio) *and* [*Twitter*](https://twitter.com/senscio)*.*

**Remembering Charlene Kinnelly:**

**Cullen:** I want to start the meeting by taking a moment to pause and reflect on the loss of Charlene Kinnelly. We were lucky enough to have Charlene at the last meeting. She has been an active participant in the Coalition nearly since its inception, and has twice provided the history of the whole system of care, going back to the turn of the last century, in a concise format that I think broke the ground for us to expound upon. Mary Lou Dyer had said in an email “never has there been, and never will there be, a better advocate for this population.” We are lucky to have known her, to have her have been a part of this, and to have had a constant champion for people with intellectual/developmental disabilities in Maine over the past five decades. If you didn’t known Charlene directly, I can tell you that you were affected by her advocacy. If you have a son or daughter with ID/DD you were affected. She’s been behind the scenes working to make positive changes to the system of care for people with intellectual/developmental disabilities. The Developmental Services Continuum of Care – she worked to make that happen. Expanding Section 29 – that was her idea. She contributed immensely towards the betterment of the world for people with ID/DD, and to the world in general. Let’s take a moment to reflect on the loss of a very significant advocate with an extensive career of service for people with intellectual/developmental disabilities. *(The group took a moment of silence.)* Thank you. She will be sorely missed.

**Featured speaker: 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.** *(*[*Click here for an audio recording of the meeting, including the featured speaker/presentation, and other related/referenced materials*](http://www.maineparentcoalition.org/november-2017-presentation.html)*)*

**Cullen:** Before we begin, I haven’t heard anyone identify themselves from DHHS, neither OADS nor OCFS. It’s come to my understanding that Dan Sylvester no longer works at OADS, so we hope to get an update on that, along with other updates. If anyone from DHHS arrives at a remote site please let us know. Today we have part three of Skip’s presentation on 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. Over the past two meetings, Skip has provided a detailed history of Pineland. We have covered it in a way that the history is encapsulated in these minutes for people to see and from which they can learn.

**Skip MacGowan:** I’m going to talk about the last 25 years – that’s a lot but I’ll try to make it brief. The Community Consent Decree – it’s the law of the land. It’s current. People tend to forget that, I think. All that we’ve talked about up until now was prologue to the Community Consent Decree.

In about 1992, there was a financial shortfall in state government, the economy was bad, and things went downhill. I think they’ve been going downhill ever since, quite frankly. The leadership of the Department shifted in the late 1990’s. The last Commissioner I had contact with on a regular basis was Robert Glover. What do you expect from government? I think at the very least you should expect honestly. He came to the CAB (Consumer Advisory Board), and admitted they were losing ground. In regards to meeting the decree, he said that they couldn’t meet it, they didn’t have the funds, and they were actually losing ground. This was a brave thing to do since his superiors, including the Governor, were saying “don’t worry, we have everything we need!”

The CAB had been doing annual audits, where it would ask parents, providers, and other interested parties to explain what they were seeing. From 1991 to 1993, every audit hearing included statements such as, “I’m on a waitlist, and I’ve been waiting a long time. When is something going to happen?” Or, “I’m not getting the type of crisis services I was guaranteed.” These were real stories, from real people saying that the system isn’t working. There were also constant statements from providers, such as, “we can’t pay our staff a wage commensurate with our expectations.” And the expectations were significant. Direct service work, such as that performed by DSPs (Direct Service Professionals) is tremendous, it requires insight, intelligence, and so many other characteristics mismatched with the wages paid. This comment has been, and remains to this day, pretty consistent. Parents were saying that the providers are good, but the staff turns over all the time; just when their children started getting to know someone he or she would disappear. Glover was the first one to acknowledge that waiting lists did exist. By 1993, Glover came to the CAB and said he couldn’t do this, and that the CAB ought to do whatever it could to make it better because he couldn’t. Mickey Boutilier, he was the chair of the CAB at the time, and he’s probably in the top five for who’s made a difference in the state of Maine; he was a remarkable man. He said that we’d go back to court. That’s an easy thing to say, but a hard thing to do. There was about a year of saying this is unacceptable, you’ve made a commitment which you are not meeting. The consent decree was a perpetual injunction, a promise, but people started saying that all of the bits and pieces are in place to make this happen so it’s okay. David Gregory was sensible in the way he approached it: It was done when it’s done, and not all the pieces are there. That was hard on the State. Lincoln Clarke was a believer that state governments made commitments and followed up on them. He was the one who said the pieces are all there, all is good. Maybe they were, I’m not saying they weren’t. Mickey kept saying the systems were there for compliance, but there’s no commitment, no guarantee, without court supervision. I think he’s been proven right over, and over again.

The State moved to dismiss the decree saying everything was in place for compliance. It wasn’t; audits were completed which proved that. Negotiations over what was left to do culminated in the Community Consent Decree in 1994. The court, eight years ago, said “well, all the pieces are in place for compliance and the State is assuring us they’re committed.” Maybe they believed that, I don’t know. Prior to 1994, the people doing the work, compliance with the consent decree, were engaged in delivering services. Almost all the key players had worked at Pineland and knew what they were fixing, how bad it had been. After 1994, there was a distinct shift in how things were discussed. Things became more legalistic. Full compliance with the consent decree was still expected, but people kept saying they had substantial compliance and the mechanisms for compliance were in place. There were a few years of serious attempts to do better, though it didn’t work well. Incrementally some things got better, but some things got worse. As I said, Glover was last Commissioner I had contact with on a regular basis, his commitment was real and his honesty was the greatest thing he could offer. Honesty led to a continuing battle with the CAB, which was comprised of volunteers like the OAB ([Maine Developmental Services Oversight and Advisory Board](http://mainedsoab.org/)) is now, including parents, providers, and a couple of advocates. All they did was tell the truth. This raised concerns. The annual audits were rather devastating; having hundreds of people all over the state come out and say the promise is there but they weren’t seeing any actions, that the waitlists were killing them, and so on. The CAB documented everything, gave copies to the Legislature, and followed up. The least we can expect of government is if it makes a commitment, the *very least* it can do is follow through. Arguments went on for years; through the first four years of the decree, there were arguments regarding how much progress had been made. The truth is, it was very finite progress. The early days were marked with a “let’s do everything and see what works,” attitude. People said, “we don’t have the answers but we’re willing to try anything with the potential to make things better.” Maximizing potential is a simple thing – ensure people get what they need to lead good lives. It wasn’t happening. After four years of telling everyone it wasn’t happening, and hearing it from the public, they made a request that the court reassign a court master. Lincoln Clarke faded out after saying everything was in place, and the State said it was complying. I’m not sure that full compliance with any of the decree ever happened, and I don’t think they continued to think it was worth working towards. The CAB was angry because the State had made commitments, and wanted to force the issue. And the CAB had a lot of allies. When state government is honest, and the Legislature is provided with all the information, it is more likely to say, “gee, this isn’t so good.” If the Legislature is kept in the dark or told lies it’s more likely to take the easy way, which doesn’t require spending money. The task of the CAB, and the OAB now, was to balance this out. The Department wanted credit for what it was doing; the CAB gave them credit, stated they knew the Department was trying, but more was needed. They needed to see budgets, whether they get passed or not is not the issue, because the budget states the short-comings of the system and what it will cost to remedy those short-comings. With this, you can at least have an honest debate in the Legislature. If you say everything is fine, the Legislature isn’t going to give you more money. Truth tellers are the best we can hope for.

We went to court to fight the dismissal of the decree, and were denied by Federal District Judge Single. The first time through it was accepted on the grounds that all the pieces were in place, it could work, and the court was willing to give the State the chance to do it without supervision. Pine Tree Legal appealed this ruling to the First Circuit, presenting the same type of evidence as the first time through, but with more focus on the community. This was happening concurrently with the Pineland tipping point, where people saw how expensive Pineland was for very few people, no one was thrilled about how it was doing, though it was far better than before it was still an institution and it could only get so “good.” And, the concept of normalization had taken hold, where if you want someone to behave more normally it must occur in normal environments, which Pineland was decidedly not. It had to happen in the community. Pineland was down to less than 200 people, all of whom had to go to court annually stating why they were still at Pineland. A lot of parents still didn’t trust the community, and you can’t blame them for that, Pineland had been all many of them had known and they viewed the transition to community supports as risky for their children. At some point it was said, possibly by Ron Welch, that the time had come to acknowledge that Pineland was never going to be right. There were two years of arguments, with parents who clung to Pineland, who couldn’t envision the community supporting their children. However, the community system had been growing for 30 years, and it was well-run, well-trained, and pretty well-funded, though never enough to pay a living wage for DSPs, but the community system was there and the programs were good. It was expensive, it was not as focused as our system is now. It was basically, “you have an idea, we have some money. If it works, good; if not, we’ll move on to the next thing.” That has all stopped. There hasn’t been a whole lot of experimentation over the past 20 years, instead everyone is just trying to hold things together and get basic services.

So, the appeal went to district court in Boston, where Judge Coffin, originally from South Portland, was the chief judge on panel. He asked simple questions such as, “do you have the respite beds promised? Enough so every client can get 14 days of respite per year?” The response was, no. Judge Coffin quickly pointed out that compliance with the decree wasn’t some sort of game where you touch home base and say, “there, we won,” and move on to a different game. At the same time this was happening, Pineland wasn’t going to be the only Consent Decree in Maine, AMHI (Augusta Mental Health Institute) was having lots of problems, and a successful suit was filed there too. Suddenly there were other people demanding money from the State. As tends to happen, the State started pitting groups against each other. You don’t always have to hurt someone to make someone else better; you just have to decide it’s worth doing and do it. The CAB won its appeal to the First Circuit, and Judge Coffin was clear: You get there, you stay there, and you don’t backslide. I think this is where we are again, where commitments have been made, attempts have been made at progress, but it didn’t quite make it. If someone in this rooms thinks we’ve met the Community Consent Decree, speak up now because I would love to debate you!

The goals of the consent decree were maximizing growth, development, and social integration into the community. These are nice, simple goals. Achieving these goals necessitated a planning system that was individualized, comprehensive, and very clearly documented needs and desires that couldn’t be met. Regardless of the funding available, desires and needs must be documented. This was required, and still is. The CAB was supposed to get copies, as is the OAB now, of these unmet needs to document them for the Legislature. Services were supposed to be small, integrated, and individualized. It was supposed to be a system for developing community ties, including friendships. That’s a remarkable thing, having a legal document state that friendships are important. There is also supposed to be an assessment of satisfaction, which gauges whether services received are what the individual needs and wants, and if not, it ought to be documented. I’m not sure that’s happening. There is supposed to be a crisis prevention and intervention program. We saw, and still see, too many situations in which the local police serve as primary service providers. That’s a bad sign. Police are good at many things, but being service providers for people with ID/DD is not one of them. Training was supposed to be available; training open to anyone who desired it. I’m not sure this is happening. The State agreed to provide crisis beds. Pineland was on its way out, and there were no other options if someone was in crisis and couldn’t stay in their own home. The solution was crisis beds runs by the State, twelve of them, as well as twelve respite beds. At the time, everyone agreed that twelve would be the *starting* number. I don’t think there are any private respite beds left in the state, so this is out of compliance. An anomaly with the AHMI Consent Decree was that it said AMHI wasn’t equipped to handle people with ID/DD, thus they shouldn’t be admitted. This might be true, however, there were no other options. Just because someone has ID/DD doesn’t mean that same person doesn’t have emotional problems. It’s a hard life at best. The availability of mental health services for this population is negligible; the State doesn’t do enough. There is no inpatient setting in Maine that’s attuned to the needs of this population. There were discussions about regional centers, small diagnostic and crisis centers. It seemed like mini-Pinelands were being proposed all over the state. There were probably better ways to do it, but there has to be ways in which appropriate, adequate, comprehensive mental health services are delivered.

The CAB said at the time the one thing the Department had done well was developing dental clinics, and having access to adequate medical care. Within a year of the court withdrawing from oversight of the decree we lost the dental clinic in Portland. We’re talking about complex dental services, and with the closure of the Portland clinic people must go to at least Augusta, if you’re lucky, but more likely Bangor. That’s not normal. That’s a disaster. Think about someone who doesn’t know what’s going on, who is experiencing dental pain, having to travel halfway across that state, have a procedure that invokes fear, have sedation, and then have to travel halfway across the state to return home. On top of this, there is likely a long wait for these services. I don’t think they’re in compliance with this.

The decree included the continuous development of employment, recreation, and spiritual activities, all of which require access to reliable transportation. Transportation appears to be a continuous issue. There must be a way to make something like that work. More and more, the State is saying let the providers provide transportation. I’m not sure that their reimbursement reflects their desire to have providers provide this service. Normalization is wonderful, but it’s important to point out that group shopping trips are not normal. I don’t know what you learn from group shopping other than not to do it. It’s a herding experience; it’s checking a box. Normalization dictates going shopping one-on-one, where someone can actually learn how to shop. Lack of transportation necessitates activities that ought to be done one-on-one, such as shopping trips, instead be completed as groups. This is a huge problem.

Throughout the annual audit processes and beyond, the CAB had been constantly hearing from families that they needed support. Families wanted to provide care for their children but they needing help doing so. The decree stated that families, which were to be defined by the person, had the right to support, training, and the promise from the State that it would be there in the event of a crisis, and it would be addressed in a timely fashion.

One of the most important aspects of the consent decree was that it mandates that unmet needs be documented, shared with the public, and budgets written to address them. We need to know about unmet needs – who is waiting for what, and why. The sooner we have that information and more often we hear about unmet needs, the more likely the Legislature is to fund them. I believe that the Legislature wants to do what’s right and will, if legislators are shown what’s right and shown what’s wrong. It’s on us to tell them over, and over again. They need to hear voices consistently saying this is a commitment, and that pointing to the golden moment when Pineland was doing its best and the community was growing, is not sufficient. Technological advancements can make all the difference in the world. There are so many wonderful advancements and opportunities, from which the elderly, children, and this population would benefit. These populations have the shared interest of making these services perfect. They won’t be, but striving for perfection is the only way you make progress. What we expect from everyone in this game is honesty; if people tell the truth we can deal with the situation.

If you haven’t, I highly suggest you read the [Community Consent Decree](http://www.maineparentcoalition.org/uploads/2/6/1/1/26115022/23_community_consent_decree.pdf). I’m going to read a section from the decree, Section X “Resource Development,” number 14:

*“While the development of safe, healthful and integrative community resources for persons who live at Pineland Center shall remain a priority for the Defendants, such development shall not proceed without simultaneous development of similar resources for persons currently residing in the community but needing similar resources for their own well being.”*

This language expanded that class for community members. The decree laid out the minimums – the minimum level of services to be provided. We haven’t met it and that’s a real crime. We have a decree, the court has lapsed jurisdiction and oversight, but it hasn’t said the decree doesn’t count anymore.

In 2010, the State filed a motion for relief from judgement regarding the Community Consent Decree. The State continued to say that all the pieces were in place, it will reach full compliance, everything will work well, and the CAB/OAB will be there to ensure the Department is on track. [On March 19, 2010, the court granted the State’s motion](http://www.maineparentcoalition.org/uploads/2/6/1/1/26115022/order_on_motion_for_relief_from_judgement_2010.pdf). The judge lapsed jurisdiction, but it didn’t lapse the notion that the state would continue live up to the decree. If you’re not angry, you should be. The State has an obligation to do better, and it needs to hear that from us loudly and often. Things *can* change, and it starts by talking about it. I’ve taken up a lot of your time, and I apologize for the endless talk, but some of it might make a difference if we believe that these things happened once and could happen, or are happening, again. People with intellectual/developmental disabilities, parents, family members, providers, and other stakeholders came together and said, “this isn’t good enough, we can and must do better.”

There is a lot I’ve learned over the years. Services for this population can be done and can be done well if we talk about it, if we push the system, tell everyone we know it’s not good enough. You should worry anytime you hear a bureaucrat say this is “welfare.” It’s not. It’s healthcare. Welfare has a connotation that doesn’t sit well for some. People view welfare as government charity. This isn’t charity, this is healthcare. One in six people in the United States, according to government statistics, has been diagnosed with ID/DD. This is a major portion of the population, and if you think about it, everyone is touched by this. Everyone is affected by the needs of everyone else. Everything is interconnected. It’s vital that we own it, and decide what we want. The healthcare debate is raging, in Maine and nationally. The undercurrent of the issue is this is healthcare for people with ID/DD – it’s expensive but it’s what’s right. And, compared to a lot of what we put our money into, it’s an important thing. We must keep speaking up and saying this is important, and impress this upon legislators. I’ve worked with legislators for more than thirty years, and in my experience most mean well they just need a push in the right direction. Someone who was powerful in the Legislature once said, “if I get five letters on one subject that’s a landslide.” Most people don’t bother to contact their legislators. We need to overwhelm them with the facts. If we do, I believe things will work out, things will get better. It certainly can’t hurt. And the commitment? Promises were made and they should be kept. This is what the government should do; it should keep its promises. This is the system we have and it can work, and it can work well, if we push it to do so. The OAB exists, and to the degree that you can you should support it because it creates a bridge to the place you can’t get to. Confidentiality can be used as a wall, with the State saying, “oh we can’t tell you this because it’s confidential.” The intent of this decree was to create a portal, through the CAB and now the OAB, into the confidentiality, to see behind the curtain. The State has worked hard to say that it *can’t* provide information, that it won’t, that you don’t need to know, and that everything is working well. I don’t think so. The court and the State said over, and over that the Cab and now the OAB exists to keep everything in check, to tell the truth. And it tries. When the OAB asks for information and don’t receive it from the Department it’s frustrating. We can help the OAB push the issue. From what I can tell the OAB is all ears. I urge you to support that vehicle to get past the confidentiality smokescreen.

The P&A (Protection and Advocacy) system is remarkable; this is another group that should be supported. The P&A system had a vision based on Wolf Wolfensberger’s citizen advocacy model. A group of parents, in 1982 or so, got together, and I was privileged enough to chair the group in Maine. P&As have the ability to provide legal services, representation, and other advocacy services. This began as natural correspondents, then appointed correspondents – people who volunteered to be people’s friends. They would go to meetings with them, and overall help make things simpler. When it works, it works very well. We need more of that, we need more empowerment of families. Families get marginalized too easily; 99% of time the best advocate an individual with ID/DD has is his or her family. We should prize that, support that, do everything we can to encourage more of that. Volunteers fulfilling this role is a wonderful thing. Mickey Boutilier spent a lifetime changing the world by making friends, by having people come together in friendship. The Special Olympics is about sports, yes, but it’s also about friends, community, and people coming together. We need a lot more of that.

We must continually ask ourselves: How can we learn to expect more, involve people more, think more about other’s needs instead of our own? Rising tides raise all ships. It’s important that we continue to think what we can do for everyone. This history should lead us to realizing there’s hope, and united we can make remarkable things happen. I started to make a list of people who did remarkable things and it was more than fourteen pages long. People make a difference when they care enough to try. That’s all it is. There are people right now in our midst who are trying, and all they need is support. Each of us can be that support. If we want change, we must work for it; no one gives it to you. But change is possible; I’ve seen it. I’ve seen the remarkable. I’ve seen things change, I know they can get better. We must demand change.

Right now, there doesn’t seem to be much of a commitment or admittance that this is the law, the State is not meeting the standards, but is working to do so. We need people to say this, as it’s a good starting place. We need less of, “pretty close,” “good enough, but there’s more to do.” When Kevin Concannon was Commissioner, and the MHMR (Department of Mental Health and Mental Retardation) was still separate from DHHS, he said he was committed, so the thought was that he could do both so they combined departments. It was pretty good, but the Department is too big, and very diverse. It seems that the Department is always pitting groups against each other. Every decision is balancing elderly, people with disabilities, and people with mental health issues. It’s constant. There’s no fire in their blood – it’s all very calculated and bureaucratic. I’m not saying we should go back to two Departments, as I’m unsure it could ever work again, but we need more contact with the people who are running the Department. I’ve attended some OAB meetings for about a year, and I’ve never seen the Commissioner show up. That’s a real problem. In the old days, the Commissioner showed up, at least on a quarterly basis. We need more direct contact, and we should be demanding that. We should be demanding to have information and know about the Department’s stances and decisions. None of us want to find things out through the press. The OAB, of all people, has the right to know. The OAB represents you. I urge you to push back, remain involved, and recognize you have leaders among you, of whom you ought to make use.

**Peter Stuckey:** Is there a component of the Consent Decree that requires the Commissioner include the budgetary request for unmet needs when he or she submits the Department’s budget to the Governor?

**Skip:** The Department must acknowledge a budget designed to meet needs, if not it’s not meeting its duty. That list of unmet needs and the related budgetary need, is supposed to go to the OAB. If the list sent to the OAB doesn’t match the Department’s budget request, then something’s wrong there. The OAB hasn’t been getting a list of unmet needs.

**Peter:** What I found is that the request would be included in the budget, then the Governor would make adjustments (pulling that out), and when the budget came back to the Legislature it wouldn’t be there. In the last budget, it was a big deal that they included this, however, we couldn’t get them to tell the Legislature how they got the number they included in the budget or what they did with it.

**Skip:** The OAB has an absolute right to see the unmet needs. They can make the connection between what’s needed and the request. It’s about honesty. I understand fully that department heads try to do the right thing. The budget that ends up in front of the Legislature and the public has been negotiated, and ultimately is what’s good politically. However, the unmet needs are absolute. If the unmet needs are included, maybe then the Legislature can say they’re not being addressed and allocate funding to address them.

**Peter:** I could never figure out how to validate the request. For instance, the Commissioner put $6 million in the draft budget. How did she get to $6 million? And where would I go if I wanted to know if the associated cost was truly $6 million, or if it was $12 million, or $100 million, and so on?

-It was stated that the closest way to determine this is the annual cost per person.

**Skip:** There isn’t a place to go to get that information, and that’s part of the problem. The number of people served, the number of beds are what drives the budget. The process of determining what each person is lacking and what it would cost to fill that gap isn’t occurring anymore. When you can show real facts, it’s hard to say that’s not important. It becomes people and not numbers. In reality, it’s not about numbers or dollars, it’s about people. There’s an expense to doing the right thing, but there’s also an expense to doing the wrong thing. Emergency rooms that have turned into holding tanks for months for people for whom other options are nonexistent. Some things are absolute. People deserve healthcare; they need it. To decide who gets what based upon how the budget is performing in any given year is ludicrous. These are citizens, citizens have rights, and legislators represent citizens.

**Peter:** How do you get your arms around the true unmet need?

**Skip:** If things work, the OAB will someday come to a wall that must be torn down to keep moving forward. I’m firmly convinced there’s a need to go back to court. Commitments were made and they’re not being kept. The law is the law. Towards the end of the decree a lot of people spent a lot of time alleging that the plaintiffs and defendants were conspiring, undermining efforts to make progress because the State then said it didn’t have to do this because it’s not on the up and up. Good people wanted to do good things, and they worked with other like-minded people who wanted it to be done. That’s good government, not a conspiracy. When I say there’s a need to go back to court, it’s not easy. After the decree was signed, the genesis, the motion forward, the mentality of let’s build more, broaden the array of services, give people what they need, what they want, and how they want it, this all stopped being the focus. Everything was framed in legalisms. I sat in a room and listened to the State say an evidentiary hearing was never held, there was no proof of how bad Pineland was. Everyone knew, that was one of the primary reasons for avoiding an evidentiary hearing, the State didn’t want this information to come to light, let alone publicly. By the 1990’s they started using the lack of evidence as an excuse, saying, “prove it.” Or, that Pineland wasn’t like that anymore, so it didn’t matter. That’s awful, it’s horrid, and it’s wrong. If we were to go back to court the question would be what is the constitutional basis? When Pineland existed, the argument was it was false imprisonment. With a community setting that argument isn’t valid, the black and whiteness doesn’t exist. The conditions might be bad, possibly even as bad, but in the community, it’s harder to visualize, harder to present a case. Due to this it would be very difficult to go back to court, otherwise, all of the people who had been involved in the past would be willing and eager now. I don’t think the court is the ultimate answer this time. I think the answer is us. Public pressure. The courts have changed though. Previously, they listened to the silly arguments about plaintiffs and defendants working together as being a conspiracy.

**Discussion:**

-It was stated that the hot topic right now is the [OIG audit](http://www.maineparentcoalition.org/uploads/2/6/1/1/26115022/oig_report_8.2017.pdf). It was stated that Skip didn’t comment on what the consent decree included regarding reportable events and adult protective services (APS). This was an important part of the decree and one of the mechanisms of compliance.

**Skip:** The OIG report is clearly a little slice of a very big problem. Reports such as these concentrate on the worst of the worst, the deaths and major injuries. I have no idea how accurate the numbers are in the report, but the facts cannot be disputed. The federal government isn’t complaining about the fact that these events occurred, rather they’re worried about the State’s response to them, or lack thereof. The Department’s response to the OAB is that it’s confidential. The Department has said that the issues are the result of poor reporting on the part of providers, and that they will do better training. The reporting system is good when it works, everything from a dropped med to injuries can be reported. For whatever reason, the State is putting off sharing information with the OAB, and as long as they do there’s no one on the inside with access to information about what’s going on. The report is frightening, and the Department’s response is non-existent. Is anyone hearing a response that makes them feel comfortable? A proper response to the report and past failings isn’t that it’s in the past so they’re not dealing with it. If you want things to get better you work to make improvements. I think Bonnie is right, if the mechanisms for compliance regarding reportable events and adult protective services worked, this would all be a nonissue. When I was Chief Advocate we discovered that reports of abuse, mistreatment, and neglect were going to the APS network and not much was happening. When I started asking questions about that I received bizarre responses. There was an established hierarchy in terms of what the State viewed as important, the most important being state wards, people the State was responsible for, next was the frail elderly, children, and at the very bottom was MHMR. The excuse at the time was that’s “the other department.” The “other department” served that population, but APS was still responsible for investigating. Instead of truly remedying the issue, the investigations were turned over to MHMR. As such, for years instead of doing advocacy we ended up doing investigations. It was a tough time. We had great staff, who completed a herculean task fairly well. APS was reintegrated into the Department about eight years ago. I would suggest that the report suggests that APS isn’t up to snuff, certainly not meeting the expectations of the decree. Not having answers is what’s the most frightening. The report could be the first step to defunding services in Maine, and the state must be taking that part seriously, as should we all. That would be a disaster. If the system was working properly, the OAB would have known what was transpiring because it would have been seeing reports. APS investigative reports for this population are not going to the OAB. They can’t push back for answers if they don’t have information. If they had been getting these reports I guarantee the OIG report would have been different.

-It was stated that what is even more terrifying is that DHHS likely couldn’t have provided APS reports because they simply were not investigating. The OIG report stated that the Department only investigated 5% of allegations.

-It was stated that there are likely circumstances in which individuals with unmet needs are wards of the state, and therefore are highly unlikely to report said needs. This appears to be a conflict of interest.

**Skip:** This is a very good point. The OAB started questioning if the State should ever have guardianship for people they serve. This puts them in situations where there are motivations to be untruthful. It’s a conflict, and certainly an area in which we should look at other options. Guardianship is a tough issue. One of the things I’ve avoided is the complexities of tough issues. Guardianship is not simple; when it works at its best it’s quite decent, but it can be misused so easily. Instead of a helping hand it can be a clubbing hand. Making a guardianship system for whom it’s truly needed is difficult. I think it gets overused as an easy copout.

**Staci Converse, Disability Rights Maine:** Earlier there was discussion about the P&A (Protection and Advocacy) system. I want to clarify that this is different from the VCP ([Volunteer Correspondent Program](http://vcpmaine.org/)) program. Disability Rights Maine (DRM) is the appointed P&A agency in Maine. The first P&A program began in 1975, as part of the renewal of the Developmental Disabilities Assistance and Bill of Rights (DD Act) ([click here for more information](http://drme.org/who-we-are#history-of-the-p-a-system)). Being the P&A agency in Maine gives DRM the ability to file suits on behalf of people, including class action lawsuits.

**Skip:**  Also, if the Department uses the term “waiting list,” the federal standard is a wait of no longer than eighteen (18) months. Historically this is what the courts have said is more than enough time. If anyone is experiencing ten years on a waiting list, the system is not working. I’m fairly confident the feds would agree this is not a good system. The fact that the waiting list isn’t numbered, there’s no Number 1 or Number 150 on the list, means there’s no standard. Maybe that’s the first thing we should be demanding. The waitlist should be systematized. We should make demands. The decree also requires an interim plan in the event services are not immediately available. In the case of the Section 21 waiting list, the question becomes what services has the Department put in place in the interim, to bridge that gap? I believe it’s fair to say that the State has that obligation. If the State can’t meet a requirement of the consent decree, then it’s the State’s obligation to create a meaningful and instantaneous interim plan. Maybe that’s the thing we could report on, the lack of an interim plan. I don’t know. I do know that they’re not in compliance and we should be loud about this.

-A parent stated that the Department perhaps leads people to believe that any deficiencies in the system rest with the provider agencies. That the Department would be fulfilling its responsibilities if provider agencies were just doing their job. It was asked if this has always been part of the compliance rhetoric.

**Skip:**  This mentality comes from the 1990’s. Prior to the 1990’s, the Department and providers worked cooperatively with the same mission and goals. The state has slowly and incrementally removed itself from provider services, which is one way to avoid being sued. What you’ve just said is exactly what the State would say if it was sued. It was the Department’s response to the OIG report. Their job is *the* job. Providing services is the job, the rest is just support for service providers. The fact that there’s that kind of blame game is not only unfair, but altogether incorrect. Providers make mistakes, we all do, but they don’t bear the burden. Providers don’t receive adequate funding to do the job, and then they’re blamed for not doing the job.

**Peter:**  Providers also get blamed for breaking the rules, which they only do because they don’t have the resources to do it right and by the book. They’re reorganizing their resources in ways that don’t follow the existing rules to provide adequate care, only then to have their integrity challenged and potentially compromised. This is a clever way of the Department downsizing the commitment. It’s so insidious when you hear the same excuse over, and over again, “we don’t have the money! Who are we going to take it from?” There’s plenty of money out there. We have all the resources we need, we just don’t have control of them.

-It was stated that another reason the Department often gives is that the waiver is capped through CMS. They tend to throw blame on the feds.

-For Section 29, the Department is using the term “queue” versus waitlist. It was asked what the difference is.

**Skip:** When you use the word “waitlist.” you’re subject to the fed’s standards, which requires a plan to address those standards through a meaningful and fair methodology. If you don’t have a waitlist you can avoid that. As far as I know, they can submit a request for more beds to CMS. I know that there were many years when they had unused beds.

**Cullen:** Skip, thank you very much for a wonderful presentation, yet again. You’ve done a phenomenal job helping us understand the history. Thank you for all the work that went into this, and for making it come alive. I hope you’ll continue to attend these meetings. Next month will feature part four of this series. Margaret has connected with someone with lived experience to tell her story. Then, equipped with all of the historical information, we will be well poised to get back to our business of trying to solve what doesn’t work in the system. Thank you again – well done!

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

**Housing Update:**

**Cullen:** Congress is working on a tax bill. The issue with this is that it’s being hurried through Congress at a rapid pace. Congress is discussing very complex reform to a tax system that’s very complicated in and of itself. Right now, the only significant vehicle for the development of affordable housing is the Low-Income Housing Tax Credit (LIHTC); the proposed tax reform bill would eliminate two if not all three of the ways in which this is done. The House bill eliminates the Historic Tax Credit and the 4% LIHTC, and changes the corporate liability for 9% LIHTC. This is complicated, but in practice what this means is that we would see the distinct lack of ability to create affordable housing. Indirectly, both the House and Senate tax reform bills would create it a $1.7 trillion budgetary hole, which would then be offset by cuts to Non-Defense Discretionary (NDD) programs, including HUD programs like Section 8, as well as entitlement programs, including Medicaid. In order for people with intellectual/developmental disabilities to have community inclusion they need both housing and support services, both of which are seriously in jeopardy with the current versions of the tax reforms bill moving through Congress. I would like to see if the Coalition would be willing to be part of a letter to Maine’s Delegation, asking our members of Congress to be cautious, and make sure that any changes include protections for all resources for affordable housing and services for people so they can be part of their community. We need to let them know we’re very concerned about this. There are numerous other tax deductions and credits targeted for elimination as well, which would both directly and indirectly affect people with disabilities.

*-A motion to send a letter to Maine’s Delegation was made, seconded, and approved unanimously after discussion.*

**Cullen:** I encourage everyone to reach out individually to members of the Delegation, send a letter saying why it’s important to have housing and services for this population, and let them know that you’re watching very carefully.

The next meeting will be on **December 11, 2017**

**Featured Speakers: TBD. Topic: Part four 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).***