Maine Coalition for Housing and Quality Services

November 9, 2015
Minutes


Cullen Ryan introduced himself and welcomed the group. Participants introduced themselves. A motion was made and seconded to accept the minutes from last month’s meeting. Minutes were accepted.

Featured speaker: Charlene Kinnelly, Lobbyist Associate, Maine Association for Community Service Providers (MACSP) meacsp.com. Topic: A five year update to the famous “From Whence We Came” presentation detailing a history of the Continuum of Care over the last century.

Cullen: Charlene previously worked at Pineland, and has remained involved with the system of care since Pineland closed. We are very fortunate to have someone in our midst who can put such a comprehensive perspective on a system that has evolved over time. We are in the third phase of development for the system of care, which started with institutionalization, evolved to deinstitutionalization and supports in the community in kind of a one-size fits all approach, and is now transitioning into the continuum of care that we have been involved in planning.

Charlene Kinnelly: June 6, 1966 was my first day of work at Pineland – that will have been 50 years ago next June. I do believe that history is extremely important. The saying goes that those who do not take the time to understand history are doomed to repeat it. There may be some very rare exceptions, but I don’t believe that anyone involved in supporting people with ID/DD wants to do harm, but we are all victims of society. If you look at a power situation, the least powerful are the people with ID/DD, therefore they are also the most vulnerable.

Pineland opened in 1908, and at that time it was the Maine School for Feeble-Minded. It came about because of societal views at that time. There was a belief that people with ID/DD were feeble minded – their minds didn’t work right, mentally they would always be children, their minds would always be feeble, and therefore they needed to be protected from society, and society needed to be protected from them. A gorgeous piece of property was obtained in the middle of nowhere – 25 miles from Portland, Lewiston, Brunswick, and South Paris. This was purposeful; it was there because it was to be a safe haven for the feeble minded to live out their lives. At first two buildings opened on the property, one up on a hill called “Hill Farm,” and one down the hill, in the valley known as “Valley Farm.” The boys lived in Hill Farm, and the girls lived in Valley Farm. The women who supervised were called matrons – we were called Mama Charlene, etc. Pineland was a farm, and it was intended to be a working farm. The boys took care of the crops, cattle, and horses. The girls cooked, made clothes, and did all the things the girls were supposed to do in those days. The first person admitted was admitted in February of 1908; five or six people came in September 1908. A book was written after Pineland closed called Pineland’s Past. I always wondered what life was like for the first individual for the seven months before other individuals were admitted. I discovered that the first Superintendent, who was the director of the institution, had been in an institution in Massachusetts. He and his wife moved to Maine to work at Pineland and brought this young man with them because he was from Maine originally, but Maine didn’t have institutions at the time. This is why the individual was admitted earlier. Anyway, when the first two buildings were full more buildings were built, and things continued that way.

Beginning in the 1920’s, but much more so moving towards the 30s, societal attitudes began to change. There was still the belief that individuals with ID/DD were feeble minded, but there was a growing belief that there were three classifications of people – Idiots, Imbeciles, and Morons. The idiots were the folks who were most capable. There was a growing belief in eugenics, particularly, the idiots were somehow genetically damaged. If you were a man than you could probably take care of yourself in terms of feeding, dressing, and doing manual labor, but you also were predisposed to violence and drunkenness. Women idiots were predisposed to prostitution, and would thus give birth to more defective people. The general belief was that they needed to be protected from themselves and that society needed to be protected from them. They needed to be watched and were in very strict isolation. There was a woman I met who went to Pineland when she was a teenager. She was born at AMHI (Augusta Mental Health Institute), adopted when she was four, her adoptive mother
died when she was six, and she ended up at the girl’s school, a reformatory, because she was poor and had no family. They sent her to Pineland. Before 1900, for the most part people with ID/DD lived at home. Maine was a very rural place, where you were born is where you lived your whole life, with family nearby. It was much easier to provide support when someone needed extra support. Also, generally speaking, the more severe the intellectual/development disability the greater the likelihood that there is also some physical/medical issues. Back then, in general, people didn’t live that long. If someone had an 8th grade education they were thought to be very well educated. Folks with more profound support needs really didn’t live that long. It was possible to keep people at home. In the 1930s medical advances really began happening. This is when penicillin was discovered; various infections, pneumonia, etc. were no longer as life-threatening. Shortly thereafter World War II started. For the first time in our history men went off to war and the women went to work. The ability to care for a family member was far more challenging. At the same time, when soldiers began to return wounded there was a huge push to deal with brain injuries, to create medications to treat seizures. All of that was happening at the same time, in terms of people living longer, pressure from families to place their sons and daughters in the institution, and fewer people available to staff the institution because they were working elsewhere at wartime. Overcrowding began and continued until Pineland’s closure. If someone needed a place and Pineland was completely full you pushed the beds closer together and made room for another bed. That happened over a long period of time. The philosophy had gradually changed over time; people then began to view people with ID/DD as suffering from mental retardation, and people were broken out into three groups: Educable, trainable, and custodial. Society at the time thought that there had to be a cause and ideally a cure for this condition.

It was asked how the determination/diagnosis was made regarding someone with ID/DD.

Charlene: That’s an excellent question. As far as I can remember an IQ of 70 was considered the educable cutoff point. I met a lot of people who, had they not lived at Pineland, would not have been considered ID/DD. Back then if you were poor, didn’t have someone to take care of you, and needed extra care but couldn’t live at the poor farm you went to Pineland. If someone was poor and not feeble minded he or she went to the poor farm – that was it for public support.

Someone from the group recalled a man who was considered educable, however he had a cleft palate, causing a speech abnormality. Intellectually he was fine, but regardless he was institutionalized. This was not unusual for the time.

Charlene: That is very true. I remember going through old records and there was a letter written from what would today be a Selectman to the Director of Institutional Services describing someone who was on the waiting list who lived in that Selectperson’s community. The letter stated that the individual was living outside, people brought food to the porch, but that it was getting cold and the individual really needed to be in by winter. These were the type of referrals to Pineland.

A parent stated that her son is 38 and lives at home. When he started school his IQ was 68 and he was considered educable.

Charlene: If you could read or write you were educable. You were trainable if you could dress and feed yourself. If you needed support for these activities you were custodial. This was also the birth of genetic testing. People who had Epilepsy prior to anticonvulsants were in danger of epileptic episodes causing more brain damage. Some of the anticonvulsants were so powerful they caused terrible side effects, but for the first time it was possible to prevent further deterioration.

Prior to the late 1950s, when it became known that a parent had a child with ID/DD the advice was to put them away and forget about it. It was not an accident that the rules stated when a child went to Pineland families couldn’t visit for the first six months. It was thought the sooner they adjusted the better. After the first six months, families could visit on the first Sunday of the month from 1-3pm for “Visitor’s Sunday.” For the entire history the family group, Pineland Parents and Friends, met on the first Sunday of the month at 3pm, immediately following Visitor’s Sunday.

It was asked if when WWII was over if there was still pressure on parents to put their children away as part of a societal stigma.

Charlene: The 1950s were a changing time. Most of the medical community still recommended putting your child away. When doctors originally went to medical school they learned that these are feeble minded individuals with no potential for learning, and they need to be protected. Attitudes evolved, but the general public’s attitude tends to be behind.

It was stated that throughout the mid-century the way of thinking was very much “leave it to the experts.” If a parent had a child with a disability the thought was “don’t try it at home, hand it over to the experts.”
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Charlene: One of the first people I met at Pineland was a guy named Freddy. He had been expelled from school at the age of five for lewd and lascivious behavior. Either you can’t be that when you’re five years old, or every five year old behaves in that manner. It wasn’t until the late 1950s that families started getting together and saying “I don’t want to put my kid in there.” When I first started as a social worker I remember writing letters to families saying “don’t come visit we’re in quarantine with hepatitis,” or the measles, whatever the illness, because it wasn’t very clean and it was overcrowded. Families started getting together and saying if schools won’t educate our kids we’ll do it ourselves. They formed an Association for Retarded Children, which became what we know today as ARC. Uplift started in the kitchen of the home of Bunny and Bob Cummings. There were seven families who started to meet on Mondays in the basement of a church. Bunny was the teacher on Monday, the bus driver on Tuesday, and the lunch lady on Wednesday, with a break on Thursday and Friday when other families performed these tasks. Though formal education may have been lacking, at least children were socializing and learning to interact. This was the start of community services. When the children were older school-aged programs came along; when the children were through their schooling group homes and workshops opened to support their kids.

In the early 1960s with the Kennedy administration, for the first time in the history of this country, we saw the beginning of federal funding of human service/public service programs, funding for basic supports for people outside of an institutional setting. This was also the birth of the Civil Rights movement, which brought with it many lawsuits and institutional reforms. The first lawsuit filed was in the early 1960s in Alabama. Maine’s lawsuit wasn’t filed until the mid-1970s. Courts were starting to really get involved. In the early 1970s Congress passed the first education bill that mandated schools educate all children regardless of handicap. It took seventy years for things to begin to evolve. The custodials were the first people to begin leaving Pineland. They were placed in nursing homes or 100-bed boarding homes. Society turned around a few years later calling out appalling conditions in these facilities, when society did it in the first place.

In the 1970s, when Maine’s lawsuit was filed, we were fortunate that the Governor at that time, Governor James Longley, brought sensitivity to the issue as his best friend was the parent of a man with Down syndrome. Governor Longley’s son, Congressman James Longley Jr., became this man’s guardian when his parents died. Governor Longley had a real interest in ID/DD. The Attorney General at the time was Joe Brennan, who also had a pretty strong commitment to individuals with ID/DD. They decided that rather than fight the lawsuit and litigate they would use it as an opportunity to improve services for everyone. The lawsuit was filed in 1975, and in 1977 Maine statutes were totally revised to have institutionalization as a last resort, and community the first priority. In 1978 the consent decree was signed. The standards in state law and the consent decree were pretty much the same; the difference was five words in the statute “so far as resources permit.” Once the consent decree was signed the class members would become a protected class; the state had to provide for the needs of the class members. Originally there were approximately 1400 class members. If state resources permitted, others, if they were eligible, could have access to services as well. Governor Longley first put money in to develop community services. Maine became the first state to be released from federal court supervision. In the original lawsuit, Appendix A was the institution, and Appendix B was the community. Appendix A was released from active court supervision in 1981; Appendix B was released from active court supervision in 1983. Maine went back into federal court supervision a few times between then and now. The population at Pineland became smaller and smaller over that period of time until Pineland closed in 1996 – we are coming up on 20 years since its closure next spring.

We collectively did it; we were the 5th state to do it. We taught society that people should not be segregated, they should be fully included as part of the community, their needs can be met, and now we’re trying to hang on and go from there. Things evolve, but everything comes from what was before it. My experience has been that it takes five to ten years to really complete a cycle. I was looking at some of the earliest minutes of the Coalition. It was either June or July of 2010 that Bill Hughes came to announce that they decided to use the SIS (Supports Intensity Scale) to do resource allocation and that they had signed the contract. It is almost 2016 and we’re finally going to be using the SIS to do resource allocation. Change takes a while.

Someone commented that things do appear to move in cycles – sometimes appearing to take a couple steps forward, and then a few steps back. There was discussion regarding how society criminalizes school behavior instead of having the teacher and parents take care of it. Children with behavioral issues in school are having the police called in. The group discussed zero-tolerance policies.
Charlene: I think society in general is scary these days. This is going to sound trite and I don’t mean to, but it seems now everybody is treated poorly. Freddy was thrown out of school because he was feeble minded – this was a different kind of treatment. Bad things happen, but they don’t necessarily happen because someone has a disability.

It was stated that it seems when there is little money there is not as much deviance; when there is more money there is more deviance.

Charlene: A lot of times it’s false choices. Why do we have to choose between a homeless Veteran and a person with ID/DD? These are false choices.

It was asked when the most recent consent decree ended.

Charlene: There was a court order signed by the federal judge that issued a permanent injunction – the State had to maintain standards and couldn’t slip back from the agreement. A Court Master was assigned to monitor the agreement and found that things did start to slip. Early in the 1990s the plaintiffs went back to federal court and the Consumer Advisory Board, an earlier version of MDSOAB (Maine Developmental Services Oversight and Advisory Board), represented the plaintiffs. Negotiations started again and in 1996 the community consent decree was agreed to. Another Court Master was appointed and in 2007, with negotiations, state law was amended again to reflect pretty much all of the agreements the parties had agreed to as mechanisms of future compliance. Finally in 2010, the federal court released the state totally from federal supervision.

There was another lawsuit, after the state was released totally from federal supervision, regarding people on the Priority 1 waitlist who were not being offered services, despite the Department having reserved slots available. This was settled out of court and really brought this administration’s focus onto the waitlists, which again led to false choices.

Just as societal attitudes change so do judicial attitudes. The courts of the 1960s were far more liberal than the courts of the 1990s and 2000s, which were far more conservative and far less likely to have the court intervene in the government’s business. The law is on the books, but it’s pretty much being ignored on a regular basis. However, we were able to get the creation of the Developmental Services Stakeholder Continuum of Care, a group formed to make recommendation to DHHS about the future, into the state budget. This group included this Coalition, SUFU (Speaking Up For Us), MDSOAB, DRM (Disability Rights Maine), DDC (Developmental Disabilities Council), providers, self-advocates, and the Department. Their work piggy-backed on the White Paper to turn it into what the broader group could come to a consensus about regarding the description of the future of the system of care. We’re trying to hold the Department’s feet to the fire so they take it seriously, which we will always have to do.

It’s unbelievable that it has been nine years since this Coalition began. I’ve been a provider all my life, but I firmly believe collectively the more we can do to minimize the involvement of providers, public and private, the more successful we will have become. People are much more concerned about their neighbors than the stranger three blocks away. The more your sons and daughters, brothers and sisters are truly members of our communities the better off we will be.

Cullen: Well done, thank you!

End of presentation. (Round of applause)


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Jim Houle: My younger brother was born with ID/DD in 1960. As you may know at this time John F. Kennedy was President Elect. President Kennedy had a disabled sister, Rosemary. She was a victim of a new state-of-the-art treatment back then known as a lobotomy, which severely affected her for the rest of her life. When President Kennedy came into office he brought sensitivity and family history in regard to this particular issue. President Kennedy was so sensitive to this issue he issued a Blue Ribbon Panel to study ID/DD in the United States. If this had not happened to raise the consciousness in the country it may have been many years before there was as bright a spotlight on this. I think I was the only teenager in Maine at the time who read the entire Blue Ribbon study. When my brother was born, my father was a surgeon and mother a nurse by training. My parents were unwilling to listen to the generally given advice to keep my brother at home. They began gathering friends, relatives, acquaintances, all of whom had kids with a disability, and they
The Maine Trust for People with Disabilities is truly a grassroots initiative with a volunteer Board and a cohort of people with vast knowledge in the necessary fields – the legal world, directors from social services agencies, investors, accountants, and so on. Everyone on the Board either has professional or family interest. There is a one-time fee to open an account ($500) and from that point on there’s no charge until the account goes into distribution mode, when money starts to be distributed to individuals. At this point there is an annual fee of 2% of the value of the account. We kept this as inexpensive as possible. We don’t have to call up lawyers and rack up big bills because we have lawyers as part of our team; we have someone who knows how to structure available funds so parents can chose how to invest their money.

Trusts can be set up as first party or third party trusts. A third party trust is when parents or other relatives put their money in the trust, the assets were never owned by the individual. Money can come from anyone other than the affected individual. This can be funded throughout the lifetime or upon death of the parents. There are a few parents who prefer to fund the account during their lifetime; this may make some sense particularly if you’re worried you won’t have the assets to pass on when you die. A first party trust is when the assets were owned by the individual him or herself. This can be used as a repair trust in case parents didn’t understand that if they leave something in their will it would jeopardize their child’s public benefits. This is a great way to preserve those assets. There is one major distinction legally with first and third party trusts: If my folks set up a third party trust, funded it themselves and it had supported my brother over his lifetime and there was still money in the trust it would go to whomever my parents wanted in the event of my brother’s death – Maine DHHS would have no claim on the remaining funds. By contrast, if my brother set up his own first party trust, federal rules say when he dies anything remaining in that trust has to go to the state of Maine to reimburse it for MaineCare benefits he received.

One other important part in using a Special Needs Trust is understanding that it is only part of the answer. Like the engine of a car, you need that engine to make the car go, but it’s only part of what makes the car function. The trust is money, which is an essential part in providing an individual’s essential needs. The team surrounding the individual is the rest of the
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equation that makes it work. Clients come to me and ask about Special Needs Trusts, and it is easy to talk about and focus concerns on money, but what they’re really asking is after they die who is going to look after their child. How do you use the money in the trust to build a team to create a good life for your child? You need to find that person who is going to be your child’s advocate, friend, listening post. If your child is 30, 40, or 50 years old the support team you put together may not be there when your child is 60, 70, or 80 years old. This is a growing problem in Maine in the geriatric industry. The best way to find that support is to try to create a structure – an institutional structure (agencies) or family members. If you don’t start with the money aspect, however, you won’t have as much potential to put together that essential support team for your child to live a full life.

I want to extend a note of gratitude with Charlene here. When I started putting this pooled trust together I was not networked with families with disabled members. I went to MACSP with the idea for a pooled Special Needs Trust but admitted that I couldn’t do it alone; I needed someone to spread the word. If it had not been for the buy-in of MACSP this trust would not have been launched. If anyone wants to talk more after the meeting I’m more than happy to. Feel free to call me as well; I can be reached at (207) 228-7268.

Discussion: The group asked how the ABLE Act is related to Special Needs Trusts. It was stated that there is a bill that was carried over from the last session that addresses the ABLE Act in Maine.

Jim: Regarding the ABLE Act, it is very limited as to the amount you can put in and the way it will work. It is modeled on the Section 529 college savings plan. A financial institution will need to be involved. With the 529 college savings plan, Merrill Lynch was the financial institution. They provided higher than market fees, but some of the fees were returned to FAME (Finance Authority of Maine) which used some of the money to make scholarship awards.

Cullen: Thank you very much this is great! Also, thank you for your longstanding advocacy in helping make a system like this work for all of us.

End of presentation. (Round of applause)

DHHS Update:
OADS, DHHS - [www.maine.gov/dhhs/oads]: A representative from DHHS could not attend but Karen Mason emailed waitlist numbers in advance of the meeting. Waitlist numbers: As of October 2015, there are 1218 people on the Section 21 waiting list: Priority 1 = 0; Priority 2 = 444; Priority 3 = 774. The number of members waiting for a Section 21 funded offer, and are receiving or are offered Section 29 services = 989. The number of members with a Section 29 funded offer, not yet receiving services = 244. The Department continues to offer all identified as Priority 1.

Email update from Karen Mason: As you will see there are still 244 offers of Section 29 services still pending. We have reached out to case managers and again was hoping to pass the word along that if guardians have received this award letter to please speak with their sons’ or daughters’ Case Manager. Letters will begin to be disseminated later this week from Resource Coordinators across the state withdrawing these offers as they have surpassed the timeline in rule. Note: This will NOT affect those who have responded with intent to use the service as long as the service begins within 6 months of the offer.

Legislative approval for up to 200 section 21 offers: Phone interviews for individuals on the Priority 2 Waitlist continue with approximately 75% of them completed. The goal is to finish this week. The next step is to review all documentation (waiver packets, reportable events, EIS assessment information) as well as information from these interviews to build a matrix for informed decision making. Will provide updates at next meeting.

Office of MaineCare Transportation Forums: In reviewing with OADS program Administrators approximately 50 stakeholders attended statewide. In addition several people called OMS staff or submitted information in writing. Will follow-up with next steps next month.

National Core Indicators: Teaming once again the DD Council to begin consumer surveys. The target start date is December 1st. We will be disseminating information to case manager soon. Please encourage individuals to participate in this valuable process.
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Discussion: The group wondered what is happening to the people who have applied for Section 29 who do not have offers currently pending (applied after 6/30/2015). Additionally, the group wondered what the process looks like for the phone interviews for Section 21 Priority 2 and what happens next. People stated that they had not heard the Department define specific criteria they were looking for in determining who to offer services to from the Priority 2 waitlist. The current status of the behavioral regulations was discussed. It was stated that the regulations should be reposted next week, and they will be published publicly in the paper on Wednesday. More information, including answers to the aforementioned, will be forwarded to Cullen to post on the Maine Coalition for Housing and Quality Service website.

Legislative Updates:
Charlene Kinnelly: The Governor may be calling a Special Session to deal with the proliferation of drugs in the state. One of the reasons why Peter Stuckey isn’t here today is due to the Health and Human Services Committee meeting today. The final action of the Legislative Council will occur on the 19th, formalizing what bills will be allowed to be introduced in the special session.

Cullen: On the federal level, Congress passed an agreement that would raise the caps 90% of the way, alleviating a lot of the pressure sequestration caused. The agreement lifts spending caps and suspends the debt limit until 2017. The agreement also sets federal spending through FY 2016 and FY 2017, and eases strict caps on spending by providing an additional $80 billion, split evenly between military and domestic programs – allocating $50 billion in FY 16 and $30 billion in FY 17. With this effort we should see a more rational level of resources, which is good news, but it will take a while. Relatedly, there is a sign-on letter being disseminated by the Maine Affordable Housing Coalition (MAHC) which calls on our delegation to recommend providing funding for Fed HOME, Section 8 vouchers, and funding the National Housing Trust Fund. I would encourage individuals and organization to sign on to this letter, and in addition we could sign on as a Coalition.

• A motion was made, and seconded, for the Maine Coalition for Housing and Quality Services to sign on to MAHC’s letter. All were in favor. The motion passed. The sign-on letter will be posted on the website.

Disability Rights Maine (DRM) drme.org
Stacy Converse: DRM has created an advisory council of people with ID/DD, particularly for those interested in policy type work. If anyone knows someone who might be interested in this please contact me. Additionally the Supported Decision Coalition is meeting with legislators to talk about supported decisions.

Other Business, Announcements:
• Click here for details on the information session on the second Specialized Housing Program
• People are encouraged to provide feedback on services provided by the Maine DHHS-OADS. There are forums in Brunswick on November 12th. There are also surveys online to provide feedback (Individual Survey, Family/Guardian/Correspondent Survey, Provider Survey). This is a chance to provide feedback and help direct how the system works. This is your voice at work.

Cullen: Check out our completely revitalized website 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 new 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! Take another look at the website from a parent perspective and make sure things are really clear, such as transition.

Cullen: At our next meeting on December 14, 2015, our featured speakers will be Kim Humphrey, Catherine Robertson, and David Cowing. Topic: Community Connect.

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).