July 13, 2015

Minutes

Present: Karen Mason, Jennifer Putnam, Julie Snook, Patrick Moore, Brian McKnight, Debra Olmstead, Kailen Olmstead, Nancy Dwyer, Gene Kucinkas, Jr., Julie Olsen, Jodi McGuire, Katrina Ringrose, David Cowing, Lenny Gulino, Moira Leighton, Mary Chris Semrow, Julie Brennan, Chad Marshall, Jay Collins, Pam Cairnie, Kaitlyn Wright, Richard O’Meara, Laurie Raymond, Bob Barton, Mary Lou Dyer, John Regan, Parry Blass, Jodie Benvie, Ed Doggett, Suellen Doggett, Todd Goodwin, Bob Duranleau, Cullen Ryan, Vickey Rand. Via VSee –Auburn: Ann Bentley and Darla Chafin. Sanford: Lisa Gross.

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: Dick O’Meara, Special Education Attorney, and Kaitlyn Wright, Special Education Attorney, Murray Plumb and Murray** [**www.mpmlaw.com**](http://www.mpmlaw.com/)**. Topic: An overview of informative cases on which he has been active in supporting parents and children, ensuring their needs are met within the Special Education System.**

**Cullen:** I have been approached by some parents experiencing dilemmas getting the right services for their children in the school system. We’re looking toward some potential collective action to remedy this situation, so kids can get the services they need in order to optimize their skills and abilities. I am pleased to see educators at today’s meeting; this should be a lively discussion!

**Dick O’Meara:** A good part of our time is spent on Special Education litigation; there is quite a bit of it in this state. We work with the [Individuals with Disabilities Education Act](http://idea.ed.gov/) (IDEA), [Section 504](http://www2.ed.gov/about/offices/list/ocr/504faq.html), ADA ([Americans with Disabilities Act](http://www.ada.gov/)), and the [Maine Human Rights Act](http://www.mainelegislature.org/legis/statutes/5/title5ch337sec0.html). The most important things to know under IDEA involve the definition of education. Everyone thinks of education too narrowly; most solely think of academics. Under IDEA, education involves academic achievement and functional performance, which encompasses everything else necessary to be a successful adult and transition into adult life. Functional performance includes engaging in social behavior, being able to take directions from an employer, coping with the stresses of life, pre-vocational and vocational skills, and activities of daily living. All of this is part of education. In addition, parents should know that this covers the regular school day as well as co-curricular and extra-curricular activities. This is my first piece of advice – think broadly about education. Almost every problem that could affect someone in school is covered under IDEA. The second thing to know is it does require experts; the school has experts, and parents need them too in order to level the playing field. Finding an expert who can help with your case is important. The hard part for parents is finding someone who will step up for your child in order to get services. There have been new legal changes in Maine that eliminate problems other states are having regarding having experts be able to see the child in school with equal access, in addition to the school’s experts. I am a little troubled as some districts have started to refuse to allow their staff to fill out the parent/child expert’s rating sheets, which includes rating scales with input coming from the teachers. They are saying: “Your expert can come in and observe but we won’t tell them anything or fill out their observation sheets.” This is important because teachers spend a large portion of the day with the kids and have a lot of knowledge and insight that your experts should have access to. We may have to fight this. Another new development involves a recent federal decision about records. There have been a lot of battles about records – what constitutes an education record, should parents have access to other records, etc. The federal ruling this past spring found that parents are entitled to see *all* records of the district, not just education records. This also helps to level the playing field – parents have access to all information pertaining to their child and can give it to their expert.

Due process is where we get involved. IDEA counts on parents to enforce their kids’ rights. This creates an adversarial relationship in some regards. Parents are trying to win a case where the school holds most of the cards; schools have witnesses and experts. Due process is supposed to lead to a hearing that can resolve issues in a fair and unbiased way. Before the formal hearing there is a chance for mediation. Most cases are solved during the mediation process. This is why there are a lot of filings for due process, but only a handful of recorded cases. If you are in due process stay put. Parents should hold on to their child’s placement so long as they’re fighting in due process. This is a right parents can assert without having to prove much. This also allows stability in the child’s life – if there is a change because of due process it will occur after deliberation.

Another important thing for parents to know is about the statute of limitations – how far back you can look for events in a child’s life. There was a change in the statute of limitations, limiting the scope from 4 years to 2 years. However, there is currently a challenge to that going on in federal court, which if it prevails, would return the statute of limitations to 4 years. At this point, with the statute of limitations being 2 years, parents have to act quickly. You can’t wait a while to file your claim. There are a lot of non-lawyer advocates in the community, and most are very good. This is a good place to look for initial advice - DRM ([Disability Rights Maine](http://www.drcme.org)) and other private advocates. It is a good idea to use advocates at your meeting. Most advocates know when to get a lawyer involved.

IDEA has very strict transition requirements – the transitional planning piece of the IEP must be in place when a child reaches 9th grade. Transition planning must include transition planning goals, services, and a formal plan. For individuals with ID/DD, this needs to be a full plan of services and goals that would allow individuals to live in the community, explore employment, as well as further education. There has been a push in Maine for good transition plans, but we still need to improve. The federal law is good, but in practice it hasn’t been up to par. Often times we hear “everything ends after school,” and that is the exact opposite of the federal law. Overall the statute has three purposes, to help children with disabilities get further education, to live as close to independent living as possible, and attain employment. Keep those purposes in mind at all times, including throughout the whole IEP process and in due process.

**Discussion:** MACSP [(Maine Association for Community Service Providers](http://meacsp.com/)) worked on a state transition bill this year. It easily passed both the House and Senate. The bill would establish a group to develop better plans for transition. This group would likely follow the Blueprint for Effective Transition, created by this Coalition.

It was stated that there are a lot of situations when the student is preparing to enter 9th grade, the IEP meeting for the 9th grade year occurs in the spring prior to that school year, but transition plans aren’t happening. Instead schools are saying this needs to happen once the student is in the 9th grade school year. It would seem logical if the 9th grade planning is occurring at the IEP meeting that transition planning would also occur.

**Dick:** The 9th grade IEP is supposed to include transition planning, and if the 9th grade IEP is done in June transition planning should be done at that point. It is a systems issue right now. Most people at IEP meetings are not following the law because of a lack of knowledge. Planning needs to include true transitional goals with true transitional services. Another piece of the IEP is including who is responsible. Student can’t do it alone. Having a statewide approach from a systems perspective would help; here hasn’t been a lot of individual litigation about it.

A parent stated that Children’s Services is saying her son belongs in Adult Services; yet Adult Services is saying he should be covered under Children’s Services because he is on the waitlist. Between this and the age-out being 20 years old it puts people in limbo. There was discussion regarding other states having a higher age-out.

**Dick:** In Maine the General Education statute only allows people to stay in school until they are 20 years old. This is the reason that Maine isn’t on par with other states. The change needs to happen in Maine to allow up to 21 years old under the General Education statute. People from DHHS should have been at transition meetings so there isn’t a gap. That’s the point of transition planning – so you don’t hit that huge hole in services. They’re supposed to be there. The burden is placed on the school district to bring in community resources but a lot of parents don’t know that.

There was discussion regarding who is responsible for the transition plan. The student seems to be responsible for many aspects. Teachers are often in charge of many things they often times don’t have the knowledge base to provide all of the input for good transition planning. This is a challenge. For transition planning to be successful it needs to be a group collaborative process. The school system is obligated to conduct transition meetings, and it is a struggle to get OADS ([Office of Aging and Disability Services](http://www.maine.gov/dhhs/oads/)), OCFS ([Office of Child and Family Services](http://www.maine.gov/dhhs/ocfs/)), and local agencies around the table to be active participants. It was asked who is legally responsible, other than schools. [Voc Rehab](http://www.maine.gov/rehab/dvr/) (VR) and local agencies often don’t know more than parents or teachers. The process involves getting together and figuring out what everyone doesn’t know.

**Dick:** The school is supposed to invite OCFS and OADS, but they can’t force them to come. It’s a great question. These relationships are supposed to exist through MOUs (Memorandums of Understanding). This is one of the problems with implementation.

It was stated that people are seeing some positive changes. With the WIOA ([Workforce Innovation and Opportunity Act](http://www.doleta.gov/wioa/)), there are transition requirements in terms of VR, which helps. The change won’t come tomorrow, but accountability is being written in. One issue with the WIOA is that its enactment did not come with additional resources. It was stated that this seems to be less of an issue in Maine, due to the way things are funded. The bigger issue will be ensuring shared accountability is happening.

There was discussion regarding parents’ personal experience with IEP meetings. If parents are not in the loop, or involved with groups like this, they often do not know who to invite to IEP meetings. Some parents with high functioning children may put off getting a children’s case manager, or may not have one at all. The issue with the IEP is often the line stating who is responsible. The process also assumes that educators have enough interest and want to be responsible. Things seem to roll year to year.

**Dick:** These cases are hard to litigate. If someone is not doing a good job many times there isn’t proof that something is wrong until much later. Once a child is out of school and problems arise parents sometimes don’t want to go after the school for compensation, or they are outside of the statute of limitations. Parents sometimes struggle for years.

There was discussion regarding a more recent trend with some Ed Techs. The group mentioned Ed Techs have been coaching parents who are facing their children aging out to have them miss 30 days of school or fail three classes so they could stay for another year. People also mentioned Ed Techs having confrontations with case managers. The group wondered if this was possibly due to financial pressure, or Ed Techs having too many students to adequately handle.

**Dick:** There are resource problems at both ends which doesn’t help. When Congress passed this law (IDEA) they expected resources to be available. It’s difficult. There is a lot that parents don’t know. People are trying but they often know very little.

There was a discussion regarding how this relates to immigrant families. There are wonderful people working in education but it seems the squeaky wheel is the only one who gets services for their child.

**Dick:** It is part of the culture for many immigrants to not rock the boat. They’re not in advocacy mode. It is tough to move them from that position to being active.

The group discussed the disconnect between best practices for transition and employment and how it is actually being done. There isn’t a lot of technical assistance to make sure it’s getting done in schools. People also have a lot of out-of-date information, or no information at all. The transition bill would shine a spotlight on what everyone knows about transition to improve the system. It was mentioned that the [Maine Disabilities Council](http://www.maineddc.org/) has some great smaller grants that would be ideal for this.

A parent stated that her son graduated from high school at age 17 with a diploma. Though he received support, he couldn’t do a lot of activities of daily living. Had she known about the functional performance aspect she would have done something before he graduated.

**Dick:** That is another issue. If someone receives a diploma at age 17 or 18, he or she is done with high school.

Educators in the group stated that there are system problems, alignment problems, and practical considerations. The DOE ([Department of Education](http://www.maine.gov/doe/)) is really trying to shine a light on the transition process. The DOE is much more involved with working with districts and focusing on transition, what it should look like, ensuring a collaborative team that comes to the table with knowledge of what they want to accomplish, and what resources exist to accomplish them. Without partnership it doesn’t happen well. It takes a long time to develop an effective team, and everyone has a lot to learn.

It was stated that the [Maine Parent Federation](http://www.startingpointsforme.org/) could be a great source for information and advocacy. The Maine Parent Federation provides parent advocacy as well.

One educator said that the district works hard to lock arms with parents, and partner on the transition plan. It was suggested that parents seek out resources in the district and if there is something you don’t know ask to slow down the process. Every case is different, every school is different, and every district is different. Teams change every year, case managers leave, people change school districts, and so on. You likely will not finish with the same team you started with.

**Cullen:** One parent sent this chart ([click here for the chart](http://www.maineparentcoalition.org/july-2015-presentation.html)), which parents may find useful in planning for their kids’ needs. Thank you for being here to get this conversation going, it is an important one!

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

**Featured speaker: Pamela Cairnie, Coordinator, Volunteer Correspondent Program** [**www.vcpmaine.org**](http://www.vcpmaine.org/)**. Topic: Overview of the Volunteer Correspondent Program (VCP), which formed in 1978 and plays a key role in people’s lives.**

**Cullen:** Pam is breathing new life into the Volunteer Correspondent Program, which is part of the MDSOAB ([Maine Developmental Services Oversight and Advisory Board](http://www.mainedsoab.org/)). This program is a key resource to ensure that individuals are connected to someone in the community.

**Begin presentation.** [Click here to view the presentation.](http://www.maineparentcoalition.org/july-2015-presentation.html)

**Pam Cairnie:** Case managers hadn’t been listing correspondents as an unmet need because for a while it was up to the team to find the person they were matched with. I am vying to change that. I have no way of knowing the actual number of people who need correspondents unless I get the information from case managers. Additionally, I always have been willing to go to agencies for informational meetings – if the door is open my foot is in it!

**Discussion:** The group was very interested in the VCP and expressed interest in utilizing the program – either as a resource for their children/clients or to become volunteer correspondents themselves.

**Cullen:** Pam manages to connect 300 volunteer correspondents to 350 individuals all while only working 30 hours a week. What she accomplishes is remarkable! This is a great program and if people aren’t taking advantage of it they should. Thank you Pam!

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

**DHHS Update:**

**Karen Mason (OADS, DHHS -** [**www.maine.gov/dhhs/oads**](http://www.maine.gov/dhhs/oads)**):**

**Waitlist Numbers:** As of June 2015, the number of people on the wait lists are: Section 21 – 1153, Priority 1 – 0 (all have pending offers, there are no individuals waiting to be offered services), Priority 2 – 450, Priority 3 – 738. Section 29 – 0 (all have pending offers, there are no individuals waiting to be offered services). Of the 1153 people waiting for Section 21 but already receiving or have a pending offer for Section 29 – 764. There are 417 Section 29 offers out currently, along with 24 offers for Section 21. Overall, a small percentage of folks decline the service offer, but I don’t have any specific information on that with me. Some funding for Section 21 was included in the biennial budget, amounting to a little more than $7 million, which will allow approximately 200 people to be offered Section 21. OADS has re-posted Bridget’s position and is hoping to fill it soon.

**Discussion:** It was asked whether there is a new Section 29 waitlist and how long people are able to hold off deciding once they receive an offer.

**Karen:** We are in the process of running the financial numbers for Section 29, so I can’t answer that question now. We hope to have enough funding to continue offering Section 29 and avoid a new waitlist. There are 24 people that have pending Section 21 offers; we don’t know how many of them currently receive Section 29, which could open up more available slots. It all moves very rapidly. In statute, people have 60 days to decide whether or not to accept the service. Some pending offers now have been sitting out there since January. Resource Coordinators reach back to the individual and case manager to find out why someone has not accepted the service. With 417 people there might be a percentage that aren’t going to accept and we want to know so we can be sure we don’t create another wait list if we don’t have to. It’s like a puzzle.

It was asked how OADS determines who on the Priority 2 list gets an offer.

**Karen:** That’s a good question! Prior to now we have been able to offer Section 21 to about 5 people per month. We have to look at people on Priority 1 first each month, which has typically anywhere from 1 to 4 people. We also have reserved capacity – anyone in an institutional setting or out of state to get them back into the state. Then we look at Priority 2. These are difficult decisions. We’re currently working on some type of rating system, for lack of a better phrase. As you know an individual on Priority 2 doesn’t quite hit adult protective involvement, but we’re looking at high behavioral needs, law enforcement involvement, and home situations. Last month there were people on Priority 2 who had aging parents, parents waiting to go into a nursing home until their children receive the service. These are the kinds of weights we’re putting on the system. We’re looking at all 400+ people and making decisions.

A parent stated that the decision to accept an offer is difficult. In her situation her son is having a difficult time finding a program that will take him. It comes down to either accepting a service he may not be able to use because he has nothing, or turning it down. If the offer is accepted and he can’t use it than someone else could be using it. It’s a hard decision.

**Karen:** With the new services added to Section 29 home support is an option as well. Someone may have been receiving another waiver and has to make a decision. These are very difficult decisions, and people have to weigh the short term vs. the long term as well.

A participant asked if more people are accepting Section 29 now that the new services have been added. Another participant also wondered if the reason why people are not answering the calls are due to repeat calls or calls getting kicked back.

**Karen:** There are 417 Section 29 offers and 24 Section 21 offers out – that’s a lot of vendor calls out there. Agencies are looking at their capacity and responding accordingly. That’s the dilemma. There is still a lot of room out there in programs. However, the staffing available doesn’t always match up with what the individual wants.

An attendee inquired whether there was any movement to address glitches with transportation and employment related rides.

**Karen:** There is. Gary has been meeting regularly with the [Office of MaineCare Services](http://www.maine.gov/dhhs/oms/). I sat in on the call on Friday. The group is looking at the different reasons why the transportation agencies are saying no. We want to cover all possible examples so we won’t see changes tomorrow, but we’re continuing to work through that. Initially this came about because the transportation agencies were starting to decline rides, afraid they would get into an audit issue. The employment example came up very quickly. Not every individual needs work support staff with them for the entire work week. Transportation agencies’ interpretation was that without the staff support they were not being transported to a Medicaid program so the agency can’t provide transportation. At this point I believe that is getting fixed. MaineCare understands that overall it’s a Medicaid service. We’re hoping to send out FAQs, and more direction very soon.

**Mary Lou Dyer:** If employment is outlined specifically in the plan that is sufficient for the transportation broker to provide the service.

**Karen:** The group is still tweaking the language. I’m hearing from case managers that different transportation agencies are asking for a variety of things – some are asking for the whole plan while others simply want to see one page. All of the information will be handy in EIS. This way they can look at it, or the case manager can print a simple page off and send it to them. Transportation agencies are looking for authorization from case managers saying it is a MaineCare services and it meets all the criteria. We’re trying to make it as simple as possible.

**Legislative Updates:**

**Mary Lou Dyer (Maine Association for Community Service Providers** [**meacsp.com**](http://meacsp.com/)**):** People are still not entirely certain where some bills stand in the Legislature, and we may not know in the short term. There is money in the budget for the waitlists, as Karen stated. The 10% cut to children’s programs did not go through. It will go through an independent rate setting process, which Jim Martin is on board with. There are still a couple of things we don’t know about, like where the transition bill ( LD 1061) is in the process – it went to the Special Study Table, but there hasn’t been an update since. There shouldn’t be a problem with this passing, but nothing is ever certain. I have never had to say “I’ve never seen this before, I’m not really sure” as much as I have this legislative session. It’s really tough to say right now, I hope to know more next month.

Someone inquired about the status of the SIS rate levels. Some people have said the rates are going up, while others have said they are going down.

**Karen:** Nothing has changed with the rates. What has changed is we have made the decision to remove the hard caps on the extraordinary review process. There had been a hard cap of 40 hours for additional staffing and there was a dollar amount per week for skilled nursing. Now, the review committee will look at individual situations and make decisions on an individual basis.

**Mary Lou:** For those folks that don’t fit well into the SIS, this is now an opportunity to get the right amount of services so they can continue to be successful in the community. A lot of parents and providers made comments about this and I’m thankful OADS listened to the feedback.

**Karen:** Also, people had mentioned a need for 2-1 for community supports. We’ll add that in as well. This doesn’t mean a person’s budget allocation will change – the individual will have to make the decisions based on the budget allocated. [Burns and Associates](http://www.burnshealthpolicy.com/) did a rate for that so it will be added in as well. We have made these changes based on feedback we’ve received from individuals, parents/guardians, family member, advocates, providers, and this group.

**Mary Lou**: The devil is in the details. The announcements Karen just made are huge. As we raise issues, and we’ve raised a lot of issues with OADS for them to consider, things change. It’s really going to come down to when the proposed rule comes out. Based on my calculations, we’re looking at rulemaking in September with an implementation date in January. There are a lot of moving parts. I’m cautiously optimistic. Originally it was important to us for assessments to play into rate setting. I’m delighted that we’re all still discussing this.

**Karen:** CMS ([Centers for Medicare and Medicaid Services](http://www.cms.gov/)), requested additional information, as was reported at last month’s meeting. Specific to the SIS ([Supporting Individual Success](http://www.maine.gov/dhhs/oads/disability/ds/sis/)) initiative, there weren’t a lot of questions. The majority of the questions were on the HCBS (Home and Community Based Services) transition plan. I was surprised there weren’t more questions on the SIS, but I believe we’ve done our due diligence and taken feedback from public sessions and put it in play for CMS to see.

**Cullen:** I’ve been pleased as the changes have unfolded, and that OADS is still open to feedback in order to optimize the system.

**Mary Lou:** The rate setting for Section 21 will still go to the Legislature for a public hearing. This is thanks to wonderful work by parents testifying against LD 1236. Everyone was very organized. The best vehicle for information is the Friday morning OADS SIS calls.

**Cullen:** We would love to be able to post notes from that call on the Coalition website.

**Housing:**

**Cullen:** I will be inDC this week meeting with our Delegation. The THUD (Transportation-Housing and Urban Development) budgets from the Senate and House don’t line up. The Senate bill is not quite as bad as the House bill. They will be fighting over the summer and will likely come together late this fall. Senator Collins, as Chair of the Senate THUD Committee, plays a key role. The Senate bill provides almost adequate funding levels for all HUD programs except one – the HOME program – drastically underfunding it almost to extinction. This was very strategic in an effort to look at the overall budget caps. In order to solve this the budget caps need to be raised – the same budget caps that caused sequestration. Once they start looking at caps there will be pressure to look at all of the budget caps. Included within this discussion will be Section 8 and the need to cure sequestration to restore 67,000 Section 8 subsidies that were lost. There are currently 12,000 people waiting for Section 8 in Maine.

**Katrina Ringrose (Disability Rights Maine** [**www.drcme.org**](http://www.drcme.org/)**):** There is a celebration of the ADA on July 24th in Capitol Park in Augusta. [Click here for the flyer](http://www.maineparentcoalition.org/july-2015-presentation.html).

**Other Business, Announcements:**

**Jodi Benvie, KFI (**[**www.kfimaine.org**](http://www.kfimaine.org/)**):** We are looking for creative solutions around roommate issues. A young woman is looking for a female housemate. This person could be someone who does not receive services who could be a supportive roommate. It could also be a person who is on a waiting list and perhaps living with family and could move out but does not have housing and would be willing to be a supportive roommate. Another possibility is someone who is receiving services from another agency or someone who might be interested in sharing KFI staff with her. She does not want to live by herself and is preferably looking for someone with similar interests. We are open to all kinds of solutions. She wants to live in the Westbrook, Portland, or South Portland area on the bus line. If someone has ideas please connect with me. [Click here for more information](http://www.maineparentcoalition.org/july-2015-presentation.html). *(After the meeting information was sent to Cullen regarding a shared living housing model.* [*Click here for more information*](http://www.maineparentcoalition.org/july-2015-presentation.html)*.)*

**Cullen:** Check out our updated 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 be right in the minutes. The website can always use more pictures!

CHOM ([Community Housing of Maine](http://www.chomhousing.org)) will be moving offices by the end of the summer. If all goes as planned we will be able to host meetings one block up the street. August’s meeting will most likely be the last meeting at this location.We are working on finding microphones that offer better sound quality in hopes that the experience for the remote sites will be improved.

**Cullen:** At our next meeting on **August 10, 2015,** our featured speaker will be **Jim Martin, Director, Office of Children’s and Family Services. Topic: What’s New at OCFS.** Also featured will be **Maura McDermott, Parent. Topic: Training Parents as Advocates for Special Education Services.**

Unless changed, Coalition meetings are on the 2nd Monday of the month from 12-2pm (307 Cumberland Ave., Portland).