January 9, 2017

Minutes

Present: Karen Mason, Bob Murray, Mary Chris Semrow, Debbie Dionne, Kim Humphrey, Katrina Ringrose, Margaret Cardoza, Tyler Ingalls, Joan Rogers, Joanna Bulger, Luann Lawler, Rob Lawler, Caron Murray, Peter Stuckey, Emily Haugh, Cathy Register, Tracy Huller, Gil Moreno, David Cowing, Glenda Wilson, Sally Mileson, Jamie Whitehouse, Jerry Silbert, Arthur P. Clum, Rachel Dyer, Jennifer Putnam, Nancy Murray, Cullen Ryan, and Vickey Rand. Via Zoom – Bangor (UCPofME): Andrew Cassidy. Sanford (Waban): Morgan Jones. Biddeford (Community Partners, Inc.): Meg Dexter. Auburn (John F. Murphy Homes): Ann Bentley, and Darla Chafin. Winthrop (Autism Society of Maine): Cathy Dionne. Brunswick (Independence Association): Nonny Soifer, Ray Nagel, Patrick Moore, and Colleen Gilliam. Gardiner (Uplift): Beth Jones, and Charlene Kinnelly. Orono (Center for Community Inclusion and Disability Studies): Bonnie Robinson. Misc. sites: Stacy Lamontagne, and Romy Spitz.

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.

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

**Featured speakers: Margaret Cardoza and Tyler Ingalls, Self-Advocates. Topic: Finding your natural supports.**

**Cullen:** Today we have Margaret Cardoza and Tyler Ingalls, both self-advocates, presenting on natural supports. We have been talking about natural supports for a long time. One of the primary features included in the White Paper, and subsequent [Developmental Services Lifelong Continuum of Care](http://www.maineparentcoalition.org/dd-continuum-of-care.html), was the concept of helping people to maximize natural supports. The goal is to get people into the community, maximize their natural supports, and in turn minimize paid supports, having people connected to their communities as seamlessly as possible.

**Tyler Ingalls:** What’s the number one reason we closed institutions? To have people in the community. What is the average cost of an emergency room visit? It’s a lot – more than $1,000. Previously when I was playing community sports, I was mostly within communities where people were disabled. I experienced a number of problems. I was 270lbs, and going to the emergency room (ER) every other week due to problems associated with my weight, specifically back pain. I was calling the ER every other week to get shots to alleviate my pain, I had to see a Chiropractor, and found out I had arthritis in my hips. I felt isolated and ostracized in the community.

I moved to Portland to become more involved in the skating community. One day at Happy Wheels I was recruited for [roller derby](http://mainerollerderby.com/) by someone who didn’t know anything about disabilities. Initially I was concerned about whether or not my reading capabilities would affect my participation in roller derby, as 90% of my life involves something I can’t do due to my reading proficiency. He said it would be fine, and though I didn’t quite believe it because of my previous experiences, I decided to trust him and sign up. I was accepted by the roller derby community – which is comprised mostly of people who had been outcasts in their own communities. Generally, there is a lot of segregation in our paid services; we haven’t quite achieved fully integrated services. Most services center around making people comfortable in group homes and day programs, solely involving people with disabilities and not people in the community around them.

**Margaret Cardoza:** I’m going start by telling a little of my story, some background information on my disability, and then describe my experience in getting natural supports – which doesn’t sound very natural, by the way!

I’m 56 years old. My mother was prescribed barbiturates and tranquilizers during her pregnancy with me. In those days, medications were handed out like candy; nobody knew the risks or possible consequences. Inevitably there were complications, so much so that when I was born the doctors requested to euthanize me, as though it was harder on the doctors than it was my parents. My parents refused, and thankfully their financial situation afforded them the opportunity to do everything necessary to keep me alive. I went to public school in the 1960’s; in those days I spent most of my time in the corner, and labeled the “R word.” I was kicked out of school, because by law they were not required to give people like me an education. I then went to a special school, run by the Catholic Church. I was segregated, and had to take a special bus away from my neighborhood, away from everyone else. Thank goodness the laws were passed ([Section 504 of the Rehabilitation Act of 1973](https://ed.gov/about/offices/list/ocr/504faq.html)) granting protections against the discrimination I, and others, experienced. I ended up going back to the school I was kicked out of! Overall, however, I had a very difficult time and had to advocate for myself constantly. Ultimately, I achieved a Master’s in Education, and got married!

Regarding natural supports, first I really think we need to change that title. It doesn’t feel good when you have to tell people it’s natural – if it’s natural you shouldn’t have to say so! We need to change the language to building community relationships, something normal and healthy. According to the Maine Department of Health and Human Services (DHHS): “Natural Supports are the people associated with the setting of the participant. They include unpaid relationships with family members, friends, co-workers, neighbors and acquaintances and are of a reciprocal nature. Such supports promote valued roles within one’s community and maximize opportunities for independence and self-sufficiency.” In the PCP (Person Centered Plan) natural supports are only referenced in one section, C14 – Building Unpaid Relationships. The Department and community want natural supports; they need to be a larger portion of the PCP requirements so that people feel valued and included.

Due to my disability, historically I have been severely misunderstood, and often given mental health labels. As such, I have been institutionalized many times. Due to this I was listed as high-risk, and given first priority so I was able to more quickly receive services. However, ultimately my goal is to get rid of them! I was assigned services through Shalom House; I was assigned a staff person, though I would have preferred to be able to make my own staffing choice. This was before computers, when crisis hotlines used to maintain large books with information on community resources. I asked my staff person to get me that book. She brought me the book, copied the entire thing, and I went through every page finding programs and activities in which I had interest. Once I identified a few groups, I had my staff to literally hold my hand and walk me into the room so I could participate in the groups that had piqued my interest. There were some groups from whom I wanted to run immediately, though I endured politely until the end. However, my worker would go back to them. It turned out I was helping my staff, who was deprived of community resources, access services for herself.

I pursued other resources, and as a result I joined a group called [Toastmasters](https://www.toastmasters.org/), where I learned how to receive and provide feedback and constructive criticism, which is really scary. Learning to speak and raise my voice was amazing. I have a room filled with awards and trophies, and I even received the highest Toastmasters award. Through this I developed my love of and proficiency in storytelling, and found [MOOSE Tellers](https://www.facebook.com/MooseTellers/) (Maine Organization of Storytelling Enthusiasts). I became the group’s Treasurer and I facilitate group activities. Being able to tell stories has been the most amazing accomplishment for me. Overall, my hope is that people have staff who make an effort to know their interests and likes, and then help people connect the dots to find those resources in the community, and if they don’t exist within the community, make them! This is how we can create inclusion and celebrate belonging. I reached out to a few agencies for help on this subject, in preparation for this presentation, and the response was that they don’t provide natural supports.

**Discussion:**

-There was discussion regarding the challenges for agencies to facilitate and create natural supports, as whether they are providing in-home or community supports, the DSP (Direct Support Professional) has to be there in order to document and bill. There appears to be a disconnect between facilitating those connections in the community and then backing off. That’s something we really need to work on; people are out in the community but that next step isn’t taking place.

**Margaret:** The Developmental Disabilities Council had a great natural support project a few years ago. Excuses are often offered by agencies, such as the turnover rate being high, which frustrates me; it feels like an insult as someone who is receiving the service. There could be an outline that provides an orientation about the people receiving services to assist new staff – things they like to do, places they like to go, etc. This would help immensely. However, there isn’t funding for this; developing unpaid relationships is a requirement on the PCP but agencies aren’t given the means necessary to adequately fulfill this. I would love to see an agency claim that it’s the natural support expert and make something happen.

-It was stated that in discussing her experience having a staff person accompany her to an activity, who then decided to stay at the activity herself, Margaret pointed out an inherent problem with the system. Staff are being asked to do for others what they don’t necessarily have themselves. It’s a difficult situation, and a hard thing to teach.

**Peter Stuckey:** I’m curious if you have thought about how we could restructure supports, beginning with children’s services, so that we are building these expectations into people’s lives, that you both have brought into your own. If kids grew up in an environment where what you’re talking about was the norm, we wouldn’t wind up with so many challenges down the road. If we as a community learned how to support children, then supporting and engaging with adults would be part of the fabric of the larger community life. I’m curious if there are things that could happen earlier in the system that would diminish the challenges you had to address.

**Margaret:** I was a Special Ed elementary educator in Washington County; my students were very challenging. My goal when I went to that school was to shut the program down – all of those children belonged in regular classrooms. It’s one thing to get special attention and support for reading and math, but it’s the social aspect, developing relationships with peers, that is missing when kids are segregated in school. This social connection is vital. I still remember isolation and shame in school; the same issues exist today. I think we should reverse the process; if I couldn’t get kids into regular classrooms I would have the classroom come to them. I was a computer consultant at the school; I gave computer presentations to the school classrooms, where peers were being educated by the special needs kids. We are really blessed, as things have become more integrated for which I’m grateful, but it needs to progress so that the “special class” is instead considered a study hall. We need to establish a more diverse and inclusive systems so once kids leave school they’ve established friendships, created peer networks, and have been truly included. It’s getting there but more work need to be done.

-It was stated that changing the “natural support” language is a great idea. The cultural language used needs to be re-examined and made more user-friendly. It was stated that there needs to be a larger umbrella for allowable services so that developing natural supports as described today can come to fruition with the assistance of paid supports. Parents stated that their children wouldn’t be able to develop natural supports without the paid supports in place to assist. There was discussion regarding different programs that help foster relationships, specifically relationships with peers in school. Though some of the programs are great, those relationships often don’t carry outside of the classroom or activity. It was stated that there aren’t public service announcements for people with ID/DD working in the community, showing who they are, what community inclusion looks like, and so on. Promoting some of these stories, showing the community more about acceptance of individuals with disabilities, could be very advantageous. Parents provided examples of volunteer activities in which their children participate, where they’re alongside their peers doing things seen as valuable in the community. Activities such as this can help facilitate relationships much more naturally.

**Margaret:** Another issue that came up for me and some of my peers is the fact that we’ve always been told “don’t talk to strangers!” I still carry that message with me today. Talking to strangers is an example of risk. I want to challenge families to allow their kids to take more risks. I was grateful for my father; he gave me enormous encouragement, pushing me to take risks, but being sure to say that if I fall down he’d be there. We need more of this.

-It was stated that the opportunity to succeed is very important, but equally so is allowing people the chance to fail.

-It was asked if Margaret and/or Tyler knew anyone with mobility issues or limited language skills, and what has worked for them in terms of being more independent and developing relationships in the community.

**Tyler:** There is [Maine Adaptive Sports and Recreation](https://www.maineadaptive.org/), as well as a network of other accessible sports, including wheelchair rugby and basketball ([click here for more information](https://usm.maine.edu/rls/accessible-maine-recreation-resources-continued)).

**Margaret:** In my story group we have a mother and her son who has a disability. He has developed relationships, a sense of comradery with the group. We don’t see his disability; we see his abilities. Once that’s in place, the sky’s the limit.

**Cathy Register (OCFS):** In the Children’s Behavioral Health planning process, the first page of the plan features a personal profile with questions intended to be answered by the individual receiving services. This is going to be a standardized case management form. This first page is very important; we want kids to attend these meetings and that very first page is about hearing from them, their wants, needs, desires, skills, etc. This information might lead to better staff matching. We’re excited about this. Additionally, I’m going to take back all of the comments I’ve heard today about natural supports; this is all very helpful.

-It was asked how OCFS would accommodate people who are verbal but are unable to effectively express their feelings or effectively respond to the questions in the personal profile.

**Cathy:** All agencies providing case management will be asked to use this form. If someone has specific needs, such as the need for an interpreter or having a family member present, accommodations would certainly be made so that all children have a voice.

-It was stated that in terms of accommodations, pictorial decision making can be helpful. It was also stated that the naming of the support system, “Behavioral Health,” has within it problems in terms of medical co-morbid diagnoses.

**Cullen:** Margaret and Tyler, I want to thank you both; this was a great presentation that generated a robust discussion!

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

**DHHS Updates:**

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

**Karen Mason, Associate Director, OADS:** Before I get into general updates, I want to say that I really appreciate the presentation and all of the feedback; I’m going to take this information back. There are some themes I heard that sparked some potential for change moving forward. One of the things we tried to do when we implemented the electronic version of the PCP was to make it easier to use as a mechanism to submit for paid services. But, I think there’s room for improvement here, to really highlight that the waiver is about skill building, moving people to their highest potential, and the ability to make those connections in the community. There’s room for growth and training there as well. Also, we need to look at how we can ensure provider agencies are able to eventually back away when they are assisting someone. As described here today, staff are assisting people to become less dependent on a staff person. We need to communicate that when they’ve provided that assistance, the skill building and training, it’s okay to step back; and we need to figure out how they can continue to get paid – possibly looking at incentivizing agencies that embrace that as a model. We’ll continue to keep this in mind for the future. I really appreciate all of these points. In our biennial plan we stress moving from a caretaker role to a supportive role. For some people services are what keeps them physically healthy, and this is important. However, we can’t forget the importance of community connections and belonging – being part of and accepted within the community is fundamental.

**Cullen:** I really appreciate your comments. We’ve talked about the difference between staff supporting people in the community versus staff standing back, evaluating how they can create situations for people to interact in the community, and maximize their ability to do so, all while standing off in the background. This is a higher-level skill and takes someone with a professional skill level. We need to celebrate and honor that. Parents have said time and time again, and I heard Margaret very articulately state today, that we all want the end-goal to be having that staff person go away, but this is much easier said than done. There are real safety aspects that have to be considered alongside numerous other factors. It’s not a simple concept, but if we could transform our system so that it’s at a point where there is a person with higher-level skills facilitating this we all would be better for it.

-It was stated that this idea is similar in nature to the role of a job coach. The ultimate job of a job coach is to work themselves out of a job; to slowly fade back to the point where he or she isn’t needed anymore. Instead, we’re talking about staff acting as life coaches, supporting people to make connections with the community and slowly fading into the background. There are individuals who may never be able to have staff fully out of the picture, but we should work to get them as close as possible.

**Waitlist Numbers: Section 21 – 1399: Priority 1 – 0; Priority 2 – 456; Priority 3 – 943. Section 29 – 0.**

**Karen:** In terms of the Section 21 rule-making process, the rule along with all of the comments are sitting in the Attorney General’s (AG’s) office. It will likely take another few weeks to go through the AG’s office, and get approval from the Commissioner and Governor. As such, we’re looking at mid-to-late February for final approval of the rule. For the Section 29 rule-making process, the comment portion is almost complete. As you may know Nikki Busmanis has left her position with OADS; we will be posting her position by the end of this week. Calls that would normally go to Nikki are coming my way for the time being. There are a few other things coming this year as well. We’re starting the planning process for another Community First Conference – targeting holding it sometime in May. If anyone has ideas in terms of presentations for the conference, please reach out to me through email (Karen.Mason@maine.gov). Additionally, we are renewing our district office quarterly provider meetings this year. Also, once the Section 21 rule is approved, the plan is to schedule public forums like we have done in the past so that we can walk through the changes and updates with members and families. I anticipate scheduling five of these across the state, likely sometime in late-March, early-April.

**Cullen:** I want to suggest using this Coalition as one of the forums.

**Karen:** We will definitely take that into consideration. We could possibly add it as an additional forum, since the Coalition meets during the day it works for some folks whereas the public forums tend to be in the evening. Also, the Governor’s budget was released late on Friday, January 6th, so there will a lot of work with the Legislature over the next few months.

-The group asked for an update on the Section 29 waiting list.

**Karen:** We don’t have a waitlist for Section 29; Emily continues to make offers every month. I believe she’s continuing to make approximately 50 offers per month.

-It was asked how long the wait is for Section 29, between application and receiving an offer of services. It was stated that people have been waiting for up to six months for offers. It was added that if the wait is more than 90 days it technically constitutes a waitlist, per the regulations.

**Karen:** I’m under the impression that the wait is about three months. I didn’t think it was quite that long. I will check with Emily and report back.

-It was stated that since no one is on the Priority 1 waitlist, it stands to reason that there are a number of people who are in the vendor call process. It was asked how many people are in this process currently. It was also asked how many people exhaust the maximum timeframe allowed to obtain services and have to go back to the very beginning of the process.

**Karen:** I don’t have the answer to this. I will check with Emily to see how much of that she tracks and get back to you.

**OCFS, DHHS –** [**www.maing.gov/dhhs/ocfs**](http://www.maing.gov/dhhs/ocfs)**:**

**Cathy Register:** After last month’s presentation there are no new updates.

-As a follow-up to last month’s presentation, it was asked if OCFS participates in school transition fairs, as opposed to solely relying on the [Transition Guide](http://www.maine.gov/dhhs/ocfs/MSK.HDBK-update%286.23.16%29.pdf). The guide is great, but it lacks interactivity, from which many people would benefit.

**Cathy:** I’ll have to ask Teresa Barrows (Behavioral Health Director, OCFS) and get back to you. *(After the meeting Cathy stated that when OCFS knows about resource/job fairs hosted by schools, they send someone to answer questions, provide guidance, and hand out materials to attendees. OCFS is more than happy to attend any future resource/job fairs and would invite individuals to contact Children’s Behavioral Health when one is planned.)*

**Karen:** I know when we’re asked to participate we always make contact with OCFS and they typically participate as well.

**Housing Updates:**

**Cullen:** As I reported last month, the Federal government is operating under a Continuing Resolution (CR), which funds the government through 4/28/17. The CR had to be within the mandated FY 17 budget caps, meaning small across the board cuts to FY 16 spending levels, which were already inadequate for renewal funding for programs such as Section 8. Due to this, at least through April, Federal programs will have less money than in previous years, let alone the increases needed to keep up with inflation and increasing costs. President Elect Trump announced Dr. Ben Carson as his pick for HUD Secretary. It has been suggested that Dr. Carson will likely act as the public face of the Department – meeting with housing leaders around the country, listening to local concerns, etc. Rick Lazio, who has a range of experience, is looking likely to be selected as Deputy Secretary, likely handling the day-to-day operations at HUD. We’ll see what comes to be. We do not have an update on the HUD 811 program, which is supposed to allocate rental vouchers for people with extremely low-incomes, with the intention of them going to people receiving, or on the waitlist for, ID/DD services. It would be great to have David Projansky attend next month’s meeting for an update on this.

**Karen:** I will get an update on the HUD 811 program for this group.

**Legislative Updates:**

**Charlene Kinnelly:** As Karen stated, the Governor’s budget was released, at around 11pm on Friday night. I’ve been through the budget once; it appears to be pretty silent on issues that affect services to people with ID/DD. However, there is one aspect I’ve noticed and have a lot of questions about. Historically, the budget has been printed with two sub-categories in the DHHS portion of the budget, differentiating between former Department of Behavioral and Developmental Services (BDS) and former Department of Human Services (DHS) programs, before they were combined and reorganized into the Department of Health and Human Services (DHHS). For example, Riverview Psychiatric Center has previously been listed as a Department of Health and Human Services program, but one that was formerly a program of BDS. This budget seems to be eliminating those sub-categories by literally zeroing out all of the money in them, and then putting it back in the budget in a general DHHS/Medicaid account. What I’ve not been able to figure out, why I have a lot of questions, is how that information is going to be made public, both for transparency and for Legislators who have questions about funding for specific populations. Will we know how many people are receiving Section 21 services, or will we just know how many people are being served across all of the sub-categories? This used to be spelled out. I’m less concerned about the specific impact and more worried about the ability to know, on an ongoing basis, how much funding has been allocated. I’m just worried about the public’s ability to know what’s going on. In any event, today is supposed to be the executive briefing of Legislative leadership, so it’s very early in the budget process. The process of actually printing bills and beginning to schedule public hearings is just starting. The rest of January will be relatively quiet, but things will heat up quickly. There is a supplemental budget to fund the State until June 30, 2017, but it’s very small and appears to mostly be very minor adjustments. I would expect that the Appropriations Committee will deal with the supplemental budget before they begin work on the biennial budget. For those who may not have heard, Representative Drew Gattine, the former House Chair of the Health and Human Services (HHS) Committee, is now the House Chair of the Appropriations Committee. Representative Patty Hymanson is now the House Chair of the HHS Committee, with Senator Eric Brakey remaining as the Senate Chair of the HHS Committee.

-It was stated that the Governor’s budget appears to increase the cap on Section 29 services, doubling the cap, exactly reflecting last year’s legislation sponsored by Representative Stuckey. It was stated that now the fight shifts from advocating for that funding to advocating to keep it in the budget. It was stated that the budget may include some additional funding for the waitlists, but further details on this are not currently available. MACSP ([Maine Association for Community Service Providers](http://meacsp.org/)) has submitted legislation, with sponsorship from the House Majority Leader, to increase the Section 21 and Section 29 rates across the board, to reflect inflation over the past decade. The rate increase, if passed, would go directly to DSP wage increases, as opposed to overhead costs.

**Cullen:** That’s great about the increase to Section 29 in the Governor’s budget. We have advocated for this, with the thought being that there are a lot of folks who would be well served with Section 29 if the cap were to be increased to 40 hours per week. This increase could allow family members to maintain employment, solve a lot of problems, and make things work better for families.

-It was stated that this is Charlene’s last week working with MACSP.

**Charlene:** I want to remain involved with the Coalition and Community Connect, I just won’t be hanging around the walls of the State House!

-The group thanked Charlene for all of her work! (*Large round of applause*).

-A parent stated that her daughter works at Marshalls and has successfully for many years. Recently, her ride didn’t show to pick her up after work. The Manager witnessed how upset she got in this situation, and as such is now requiring her to have support for her entire shift. She only has one hour or so remaining of her Section 29 services, meaning she will have to go without in other areas in order to have more support at work. It was stated that she doesn’t need support for work; her staff person would be standing there for four to five hours just to be there at the end of the shift to wait for the ride. The parent stated that she is considering contacting Disability Rights Maine (DRM), and possibly making a complaint to LogistiCare.

**Katrina Ringrose (DRM):** This seems like an extreme reaction on the part of the employer. I hope you will call us.

**Karen:** Lisa Sturtevant in our office would be a good contact for this as well. (Lisa Sturtevant, Employment Coordinator
Maine DHHS-OADS; E-mail: lisa.d.sturtevant@maine.gov; Phone: 207-287-9210). Maybe there’s a way for Lisa to assist.

**Cullen:** This story illustrates how it all ties together; if you don’t have one piece in place it can all fall apart.

**Other Business:**

* [Click here for information on Mary Lou Dyer’s retirement party, hosted by MACSP, on 1/18 from 4 to 6pm.](http://www.maineparentcoalition.org/postings.html)
* [Click here for information on upcoming Community Connect meetings.](http://www.maineparentcoalition.org/postings.html)

**Cullen:** As mentioned at last month’s meeting, we are contemplating changing the name of this Coalition. The Developmental Services Continuum of Care group is working on brainstorming alternative names. We will see where that goes and bring suggestions back to this group.

**Cullen:** Check out our website [www.maineparentcoalition.org](http://www.maineparentcoalition.org). You can find the title of any of our past presentations; Click the link, and you will go right to the minutes. There is also a forum on the Section 21 & 29 page on the website. You can log in and post questions/topics for other parents to answer. Additionally, the website can always use more pictures. Take another look at the website from a parent perspective and make sure things are really clear, such as transition. Our goal is to be an easily accessible information clearinghouse.

The next meeting will be on **February 13,** **2017**.

**Featured speakers: Charlene Kinnelly. Topic: State Legislature 101.**

Also featured will be: **Betsy Mahoney, parent. Topic: Block grants.**

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).***