

## Maine Coalition for Housing and Quality Services

August 8, 2016  
Minutes

Present: David Cowing, Debbie Dionne, David Lawrence, Dina Martinez, Debra Olmstead, Bob Duranleau, Sasha Salzberg, Adam Wilson, Jamie Whitehouse, Julie Brennan, Sally Miles, Richard Norton, Janet Rancourt, Glenda Wilson, Jennifer Fales, Ricker Hamilton, Nikki Busmanis, Liz Weaver, Charlene Kinnelly, Ed Doggett, Suellen Doggett, Ken Olson, Maura McDermott, Polly Bradley, Jerry Silbert, Jennifer Putnam, Cullen Ryan, and Vickey Rand. Via Zoom – Bangor (UCPofME): Andrew Cassidy, Bonnie Robinson, Melissa Lowe, Alan Cobo-Lewis, Frances Cartier, and Kathy Vorenkamp. Sanford (Waban): Morgan Jones. Auburn (John F. Murphy Homes): Darla Chafin, Katrina Wozich, and Ann Bentley. Winthrop (Autism Society of Maine): Cathy Dionne. Misc. sites: Andrew Hardy.

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 Sencio Systems, who has very generously covered the cost of lunch for our meetings! For more information on Sencio Systems you can visit their [website](#), or connect with them on [Facebook](#) and [Twitter](#).*

**Featured speaker: David Unger, Executive Director, Speaking Up For Us (SUFU). [sufumaine.org](http://sufumaine.org). Topic: SUFU strategic plan and employment volunteers.**

**David Unger:** Thank you for having me. For those of you who don't know, SUFU is Maine's self-advocacy group for adults who live with ID/DD. It has been in existence since 1996 in different variations. I don't call our members self-advocates; you and I all advocate for ourselves and we're not called self-advocates. We have SUFU members. One aspect that makes SUFU unique is that it is a 501(c)3 non-profit organization, and as such has a Board of Directors. We are one of a few in the country that has this setup, but more states around the country are moving towards this model. Back in January of 2014, I was retained as a non-profit consultant for SUFU with a 6-month contract, and here I am today! Professionally, this has been one of the most rewarding experiences I have ever had. Watching the transition of the decision making process has been phenomenal. I can't believe what I am learning from these individuals. As with any membership-based non-profit, SUFU's members make up its Board of Directors; SUFU's entire Board is comprised of people with ID/DD. I needed to train the Board, and the Board had to train me in order to accomplish the everyday business of the organization. I had to figure out how to educate the Board members on the financial aspect of the organization; however, in reality they trained me on what they need. We boil the budget down to very simple terms; we look at money in and money out. We bring in three cookie jars, we have a PowerPoint too, but we look at if money goes into one cookie jar, there is less to go in the others. They have the opportunity to ask a lot of questions, they take the process very seriously, and inevitably just like any other non-profit organization the Board approves the budget.

When I came to SUFU one of the first things I did was an assessment in order to make organizational changes. It was very apparent through this that we needed to give SUFU back to its membership. In the past non-members came to chapter and Board meetings, without being invited or for a specific agenda item. This got very confusing and the SUFU members felt like SUFU wasn't their organization. We created a policy to address this. The policy states that in order to attend a SUFU Board meeting, if you are not a Board member or on staff you need to be invited. Additionally, individual organizations would call SUFU members and ask them to provide testimony at public hearings as an individual and representing SUFU; members were saying yes despite not necessarily representing SUFU, because there wasn't an official policy. This created some challenges. With requests such as these, we take it to our Board, survey SUFU members, and get a consensus of what our members want. The results have been interesting, and they haven't necessarily been in sync with what people had wanted the members to do.

One of SUFU's major goals is community involvement and engagement. It was very hard to have meetings within the four walls of a provider agency. We began moving all of our chapters out of provider agencies and into community spaces – banks, community centers, other places that are free or very low rent. The response from the community has been phenomenal. SUFU's goal is to help people improve their lives; we had to figure out how to listen and understand our members' needs. So, we started a committee process and created a Chapter Representative Committee, made up of elected officials from each SUFU chapter. The committee convenes to talk about major issues affecting members. This committee

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is the nuts and bolts of what we're trying to do and it creates policies to take to the Board. One of the first things the committee tackled was support staff in meetings. Chapters reported day support staff were very actively involved in the chapter meetings, and were in turn making decisions for our members. The committee created a policy, which was approved, that stated that SUFU has the right to ask anyone to leave a chapter meeting. Whenever there is a heavy or important decision that needs to be made, the Chapter President asks support staff to leave the room for a period of time. There is a stark difference in the tone and quality of the conversation, because there's fewer inhibitions and people talk more openly and freely.

Along with our 15 or so chapters we have two specialty chapters. One of the specialty chapters is with the art department with Portland Public Schools; they were part of creating the [training videos posted on our website](#). The second specialty chapter is our sports chapter, which aims to integrate SUFU members into the local sports communities. We discovered that a lot of our members didn't know how to play sports, so we had to do some very basic sports programs. We had three members who had never been on a bike before, and they now ride them together constantly.

When I came to SUFU there was no way I could ever experience what the members go through; they had to educate me. We asked members what frustrated them most about having a disability, and the responses became the foundation of the strategic plan. We began talking about the strategic planning process at each Board meeting as part of our ongoing agenda. I'm pleased to say that at the end of June we approved the strategic plan. We even took the basic components of the plan and gave it to a subgroup of the Board and they wrote it. This is truly their plan.

I also had to determine how to train new leaders to become Board members. We received a generous grant to create a leadership development program. We retained [Lift360](#) in Portland, a leadership development organization, for this, and we just completed our second class. From the first class, four of the nine participants became Board members, and one has been hired as SUFU staff. From the second class, six of the seven participants have been nominated for positions on the Board. This process was another "aha!" moment for me; this defines, in my eyes, the concept of self-advocacy. When I first started I would ask members to define self-advocacy. They would respond by saying it meant speaking up for themselves, but when asked what that meant they didn't know. Through the leadership development program, members discovered that self-advocacy is a problem solving process. Self-advocacy is more than speaking up for what you want; it's understanding what you want, the resources you need, and developing a plan for how you're going to get achieve your goals. We have taken the concepts of the leadership program and moved them into our day-to-day activities. When we talk about decision making, we talk about the actions and reactions to the decision. We work to understand what we're talking about and what potentially will happen with the process. We go around the room and talk about it on an individual basis – we get people engaged. Our Chairperson asks each person individually, "do you understand this?" People are comfortable enough now to say no when they don't. We ensure everyone understands it before we vote. We're expanding the program with Lift360 regionally. We're involved with New England advocacy groups, and a program will start in November to engage these regional groups. Individuals have grown substantially due to this program. There are instances where people would not say a single word on day one, and then went on to run an entire discussion on the last day of the program.

One of our goals is employment. This has been a major frustration for a lot of our members. We are talking to the Board on Wednesday regarding a rough draft for an employment program that has been privately funded. The program would help get our membership employed. We would be using the for-profit sector to help do this, and we already have a private employment agency on board. This is a very exciting project for us. There is a model like this already in the state, we would simply be replicating it. The program would be limited to southern Maine initially, and then hopefully as the model grows we can take it statewide.

The bottom line is we're giving SUFU back to its membership – where they take it is in their hands.

### Discussion:

-There was discussion regarding employment and transferable skills training while people are still in high school. Preparing and training kids while they're still in school is imperative. It was stated that Voc Rehab (VR) can be challenging, and shouldn't be solely relied upon. It was stated that this isn't the only group in Maine who has trouble with employment skills. There are technical schools and community colleges in Maine; given the existing infrastructure there

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should be more opportunities for people with disabilities. It was stated many employers don't know people's abilities; we need to better communicate what our kids can do.

**David:** There are businesses out there and folks who can do the job, it's about making the right match and finding the right supports to keep the job.

**Cullen:** Philip Divinsky, Program Instructor for Food Services, at Portland Public Schools PATHS ([Portland Arts and Technology High School](#)), presented at the July 2014 Coalition meeting. He runs the Culinary Arts program at PATHS and is remarkable as a teacher. Students in his program end up running a full service cafeteria, working all of the various stations, and learning a great deal of skills. Every single student walks away with a resume which includes all of the skill sets they have developed, allowing a potential employer to look at their transferable skills. This is a great demonstration of creativity surrounding training and employment development.

**Nikki Busmanis:** Regarding youth transitioning into adulthood, the State recently applied for a systems change grant which would address barriers and challenges for youth with disabilities. This would be looking at building the capacity to increase meaningful work experiences while people are still in high school. This would also look at presenting and developing media (videos, etc.) regarding those success stories of individuals with disabilities who are working. Hopefully at the next meeting we will have good news to share about this. We want to work on addressing youth transitioning to adulthood, providing the skills and experiences early on to get better long-term outcomes. Part of the grant involves hiring parents to work with other parents to build higher expectations for their children. I'm not directly involved in the grant, but I wanted to share this information with this group.

**Cullen:** David, I want to thank you for being here and sharing this information about SUFU with all of us!

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

**Nikki Busmanis, Program Manager, Developmental Services, DHHS Office of Aging and Disability Services(OADS).**  
[www.maine.gov/dhhs/oads](http://www.maine.gov/dhhs/oads) **Topic: Proposed Section 21 Rule Changes.**

**Cullen:** Nikki is going to share some information about the proposed Section 21 Rule Changes that are in the works. We also have the Section 21 Waiver Amendment application to CMS ([Centers for Medicare and Medicaid Services](#)), which is currently out for public comment (*comments due 8/21 by midnight*). We were hoping to have a conversation about that today as well.

**Nikki Busmanis:** Thank you for having me. We are proposing some changes to the Section 21 waiver. About a year ago we had proposed another round of changes to Section 21 that included the SIS (Supports Intensity Scale). When we made the decision to pull that tool back in March we had to pull back the whole rule process. We took a step back, went into the community, and gathered feedback regarding concerns, what changes people were hoping to see, and what the Department could do better in terms of the roll out of the rule. The biggest piece of feedback we heard loud and clear consistently at the forums was that people wanted to hear directly from the Department and they wanted to hear from us in different ways. We took that to heart. We drafted a new proposed Section 21 Rule that includes some of the feedback we received. We expect that the rule will be posted at the end of this month. Between now and then we wanted people to hear messages from us that they didn't last time; what those changes are and what they mean for individuals and families.

**Begin Presentation.** [Click here for the presentation materials.](#)

-Nikki reviewed the "[Projected 2016 Section 21 Rule Timeline](#)" flowchart with the group. The "Proposal" step of the flowchart, in green, is what is anticipated to occur at the end of this month. Between the "Proposal" step (green box in the flowchart) and "Commissioner, Governor, and Attorney General Approval" step (red box in the flowchart), the Department has to go quiet and cannot respond to questions, comments, or concerns. The "Response to Comments" step of the flowchart, in orange, is when the Department will respond publicly to all questions and comments formally received during the public comment period.

-It was asked how the Department gathered feedback when creating the rule.

**Nikki:** We drafted the rule based on the comments received from the last rule proposal process, as well as what we heard through the forums in May. We incorporated that feedback in this rule, then people can make further comments during the public comment period and at the public hearing. We hear and understand the desire for more opportunities for feedback before we even draft the rule, and we will ideally incorporate this moving forward. We proposed an amendment to the

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Section 21 waiver to CMS, and in that we included certain language that now we need to change – to come into compliance with the CMS waiver amendment we had to submit a new State rule by the end of August. By going out and sharing more information about the process, like we are today, we hope to address and incorporate feedback before we promulgate the rule.

-It was stated that there are concerns that what happened last spring with the rule process will be repeated if enough due diligence isn't done up front.

**Nikki:** Last time around we heard that people didn't understand all of the changes. The rule is a huge document and is difficult to read and understand. We picked the areas where we anticipated people would have the most questions and came up with basic bulleted points to help explain those.

-Nikki reviewed the "[Section 21 Proposed Rule Changes Highlights](#)."

**Nikki:** First and foremost, there is no assessment tool incorporated into the rule change and the PCP (Person Centered Planning) process will remain completely intact. We are not changing anything about the PCP process in this rule change. With the SIS, people thought the PCP process would be replaced or be diminished, so we wanted to address this up front. We put a lot of stock into the PCP – it's a very important process.

-It was asked if physicians would be included in the CRT (Clinical Review Team).

**Nikki:** The CRT is made up of two Registered Nurses (RNs) and two social workers with previous experience working with people with ID/DD. The CRT is similar, in part, to the Extraordinary Review Committee which was included in our last proposal; it is another iteration of that, except without the assessment tool. The CRT will collect documentation from clinicians, family members, and people who work directly with the individual with the goal of ensuring the right amount of hours are allocated to that person.

-It was stated that not having a physician included is problematic. It was suggested that the process include a physician with an environmental background and some background with people with ID/DD. The standard hospitalization situation has glaring holes for people with ID/DD, specifically for people who are medically involved and are non-verbal. This is just the tip of the iceberg.

**Nikki:** This is great feedback. I would suggest that you incorporate that into the formal public comment period – we would love to hear about it.

**Jennifer Fales:** There may not be a physician on the team, but it's written in a way that allows us to consult with and pay for specialist consultations as required. We have built it into the model.

-It was stated that it appears the Department is under the impression that congenital heart defects can be treated by cardiologists; a pediatric cardiologist is needed, even for a 45-year-old. It was stated that the Department has a blind spot in regards to co-morbid diagnoses, which needs to be addressed. A parent stated that his son is getting very close to serious problems due to microbiome vegetation within the heart, that set up while under the care of the Department.

**Jennifer:** I appreciate your feedback and am sorry to hear that.

**Nikki:** Hopefully down the road, as this team is implemented, there will be an opportunity to expand and look at more medical needs. For the purpose of this rule change we're looking at having this review to make sure people get the care they need, and that it will help in the long run.

-It was asked how the CRT is related to or interacts with APS healthcare? (*Ricker informed the group that [KEPRO](#) has acquired APS Healthcare, so the group may begin seeing that name in place of APS Healthcare.*)

**Jennifer:** Currently APS Healthcare approves staffing increases. The CRT will be partnering with Department resource coordinators, who will take some of those approvals in-house, to make a better and more informed analysis, hopefully with a quicker turnaround.

-It was asked if APS Healthcare would be removed from this process altogether.

**Nikki:** Down the road it's a possibility. APS Healthcare isn't really looking at the PCP, and we believe that the PCP is the core of the process.

-It was asked if the CRT would be approving shared living and medical add-ons.

**Nikki:** The CRT will be in charge of medical add-ons for all services and increased level of supports for shared living. There will be an initial review by the CRT for people on the waiver to ensure documentation and requests for services are meeting their levels of need.

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-It was stated that with this there is a concern it will create a bottleneck. It was asked how many people will be reviewed.

**Ricker Hamilton:** We're talking about a small number of people who will be reviewed.

**Jennifer:** Around 200 to 300 people on the waiver have medical add-ons, and about the same number have increased support. With the current process there isn't a reassessment to see if people still need that increased level of support down the road. We're building in a process to look at this on a more regular basis.

-It was stated with a caseload of 400 to 500 people for one team, it would be a solid year of just reviewing existing cases.

-It was asked if the proposed State hiring freeze would affect hiring for the CRT.

**Nikki:** It wouldn't; these are contracted positions.

**Nikki:** The third highlight for the proposed rule is regarding ensuring full staff support. Currently, provider agencies that operate group homes can bill for 100% staffing, but only need to provide 92.5%. None of the other waivers do this. We're trying to align our policy to reflect the payment process. If a provider is billing for 100% of staffing, they should provide it.

-Providers commented that the range has been helpful, as it accounts for the weeks when more than 100% of staffing is provided. It was stated that some providers do monthly billing. Currently the range is between 92.5-102.5%. There are some weeks with well over 100% staffing. The original intent of the range was realizing that you can't keep that steady on a daily basis.

**Nikki:** There are instances where providers are only providing 92.5% staffing, and people aren't able to accomplish goals in their PCP. It's really basic – whatever you provide for staff support is what you bill for.

**Jennifer:** The billing method won't change so much; we're just talking about billing for what you provide. If you provide 101%, you bill for it. You will no longer be able to bill above what you provide.

**Ricker:** You get paid for what you provide, and you will be paid for that, not what you don't. We're just making it consistent with the other waivers and our federal partners.

-Provider: Historically, this was established to acknowledge staffing crises that occur depending on the economy. The reality in our state is that providers have used that margin to compensate for the employment crisis, on top of not seeing a rate increase in years. Providers have been able to just get by using that little difference to compensate for all the other unfunded mandates that come from the state, for instance the recent behavior regulations. People have been using that little bit of a difference to make things work.

**Ricker:** All of the waivers are in the same circumstances. There have been rate studies; [Burns and Associates](#) worked for years on the rate study and it was scheduled to go into effect before the Legislature put a moratorium on implementing the new rates. Some of the waivers would have seen rate increases.

**Nikki:** When we pulled the SIS, we had to go back to what the rates were.

**Ricker:** At least you're not looking at a rate decrease.

-Providers stated that they are dramatically affected by the rates. The minimum wage will likely go up in the very near future (and has already in Portland), there is federal legislation changing the way exempt status works for employees, and there are higher insurance costs. There are numerous factors pressuring this industry. At the forums in the spring people commented on staff turnover. Without significant rate changes some agencies will go out of business. It was stated this is why collaboration up front is imperative to understand the real needs all across the board.

-It was asked if members of the CRT will know the individuals for whom they are making service decisions.

**Nikki:** Members of the CRT won't know the individual themselves, but they will communicate with the people who do know them to get the full picture of that person's needs.

-It was asked who will police providers regarding billing for the staffing they provide.

**Nikki:** We won't be policing, exactly, but through auditing this would come to light.

**Nikki:** The fourth highlight of the proposed rule is ensuring members are safe. The rule proposes that providers must: Conduct background checks every two years; include background checks from Child Protective Services (CPS); and conduct background checks for adults living in a Shared Living or Family Support Home.

-It was stated that there is a dilemma regarding what to do when a background check comes back with something on it. Without guidance in this area, making a hiring decision can be difficult. This process is likely very different at every organization. It was stated that the hiring decision should be based on "what if that was my child?" However, this isn't an

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objective way to make the decision either, because many parents would make different decisions in the same scenario. This is coupled with the reality of being chronically understaffed and having to make tough decisions. Providers err on the side of caution and safety, but guidance would be extremely helpful.

**Nikki:** Currently this is up to the discretion of the providers, but if it would be helpful to be more prescriptive, that's something we could look into.

-It was stated that legislation passed in the session before last creating a direct care registry computer system, through licensing. The computer system that was scheduled to be piloted this past April, would create access based on social security numbers, and would have data that is constantly updated. This would eliminate the need for this whole proposal. It was asked what the status of this was.

**Jennifer:** We can check on that. I'm not sure of its status.

**Ricker:** I have made the same mistake of relying on one source for information with background checks. With criminal charges, unless you ask in the hiring process if something is pending, you won't know. We'll follow up on this and make sure we have the answer for next time.

**Nikki:** The fifth highlight of the proposed rule is providing opportunities for feedback. Throughout the APA (Administrative Procedures Act) rule making process there are opportunities to formally comment on the proposed rule changes: The public hearing and the through the written formal comment period. The Department is required to respond to all comments and questions in writing and post them publicly when the rule is promulgated.

-It was stated that between the proposal being posted, scheduled for the end of this month, and the end of the public comment period no one from the Department is able to talk about the rule. It was asked if there are any opportunities to provide input while the rule is being developed.

**Nikki:** With processes moving forward that will be a possibility. This time there is a tight turnaround to come into compliance with the waiver application. Moving forward it's a great point to ensure more stakeholder involvement as we're drafting the proposal. These five highlights were just the talking points that we anticipated would generate a lot of questions. There are a few other informational opportunities. There are call-ins coming up for members, guardians, and family members as well calls for providers.

- **Member, Guardian and Family Conference Calls:** Wednesday, August 17<sup>th</sup>, from 5:30-6:30pm; and Thursday, August 25<sup>th</sup>, from 4-5pm (Please call into the following number and follow the prompts to join the call: 1-877-455-0244 Pin 2072874227).
- **Provider Conference Calls:** Friday, August 19<sup>th</sup>, from 1-2:30pm; and Thursday, August 25<sup>th</sup>, from 12-1:30pm (Please use the following conference call number and pin to join the call: 1-877-455-0244 Pin: 2072874227).

**Nikki:** During the conference calls we will go through these highlights to see if there's anything we can clarify before we post the rule. We will also be sending letters to all individuals receiving Section 21 and on the Section 21 waitlist informing them of the proposed rule changes, developing a video, and looking at social media as a means of communication. We heard loud and clear at the forums that people wanted to hear the messaging in different ways. I wanted to share that another aspect of the rule we're proposing to change is for individuals served under Section 21 who are still in high school to be able to access employment services.

-It was stated that there can be language barriers with DSPs (Direct Support Providers) for whom English is their second language. In the same vein, sensitivity and cultural training would also be helpful.

**Nikki:** That's great feedback. For DSPs there are trainings specifically for individuals for whom English is a second language. But that's a great point, you need to be able to communicate.

-It was stated that since providers have a year to train their staff, they often hold off on training as a means of cost savings. This leaves untrained staff working with people, who then turnover quickly, only for other untrained staff to take their place. There are workforce limitations, and they're getting paid minimum wage, but it's not working.

**Nikki:** I can hear your frustration.

**Cullen:** Thank you for being here and talking about this. You're looking to post the rule at the end of August. It would be great to have you present at next month's meeting, where we could clear the whole agenda for you so people can ask questions.

**Nikki:** That's why I wanted to share the other opportunities to connect with us, since we will be posting the rule at the end of this month.

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**Cullen:** The transparency is great and you being here is fantastic. However, what I heard from parents and folks within the Coalition is that when the Department is making changes that affect the system, people want to feel like they are part of designing it, feel like it's theirs, so when you go to promulgate the rule we're all behind you.

**Nikki:** We're working off of the comments and suggestions received during the last rule change process. If you do have an opportunity to read the proposed rule change, you'll see some of that language. I'm sure we'll be doing this again in another year or so and having more opportunities to be part of the development will be important.

-It was asked if there was a possibility of another meeting.

**Nikki:** I'll leave that to the Coalition. We are looking at meeting with SUFU.

**Ricker:** No other state in the country did more with communication with stakeholders than the state of Maine did last time around. We're going to have someone here at these meetings each month; we value your input. We've demonstrated the extent to which we can communicate – we do need to get better. If you have questions, ask the Department directly. Talk with us, don't let someone interpret things for you.

-It was stated that the Section 21 Waiver Amendment application to CMS is currently out for public comment. It was asked if the Department is able to respond to questions and comments regarding that.

**Jennifer:** Yes; the same rules don't apply for the waiver amendment application.

**Ricker:** We're going to try to communicate as much and as best we can.

**Jennifer:** Some of this is out of our hands based on the established timelines.

**Nikki:** I really encourage people to communicate with us. Our goal is to improve communication moving forward. I'm hoping this is helpful. I've heard loud and clear earlier stakeholder involvement is critical. If there are other comments, please let me know.

**Cullen:** Thank you for being here.

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

**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.

**Cullen:** At our next meeting on **September 12, 2016**, and our featured speaker and topic are yet to be determined.

Unless changed, Coalition meetings are on the 2nd Monday of the month from 12-2pm.

*Burton Fisher Community Meeting Room, 1<sup>st</sup> Floor of One City Center in Portland (off of the food court).*