5/11/18 – Olmstead Consumer Task Force Meeting

WiFi Code: phuupluu

1. Welcome & Introductions
   1. In person: Kay Marcel, Dawn Francis, Bruce Teague, Tracy Keninger, Len Sandler, Harry Olmstead, Kris Graves, Kevin Dalin, Roxanne Cogil, Jenna Batten, Kathleen O’Leary
   2. Phone: Annie Gallagher, June Klein-Bacon, Kim Barber (Iowa Dept for the Blind), Alex Bomhoff (NAMI Greater DSM)
   3. State Representatives: Theresa Armstrong, Deb Johnson (phone)
   4. Guests: Brooke Lovelace, Raphael and Novath, John McCalley (AmeriGroup), Di Findley (ICA)
   5. Staff: Caitlin Owens, Julie Christensen
   6. Taskforce members absent: Mary Roberts, Ashlea Lantz
2. Review, additional items and approval of agenda

a. Dawn called the meeting to order at 10:10am. A quorum was established.

b. Harry moved to approve agenda; Kathleen seconds; All in favor; agenda approved

1. Review, corrections and approval of Minutes from March Meeting
   1. Roxanne approved minutes; Len seconds; All in favor, minutes approved
2. Executive Committee Report
   1. Proposed bylaw change – first reading was in March: Harry moved to approve; Bruce seconds; All in favor; motion passes
      1. Move annual meeting to July (from March)
         1. This supports the plan to move nominations later in the year, avoiding the legislative season; July meeting is vote for new members, new member first meeting is September
      2. Change to amendments process to allow changes to be made without the need for a second reading; proceed with a second reading and vote (if there is a quorum)
3. Taskforce Nominations Overview
   1. Caitlin provided update on behalf of Mary (nomination committee chair – who was unable to be in attendance)
      1. 10 seats open
         1. 8 current members’ terms are up (for three year terms)
            1. Current members eligible to reapply were provided a short-form; not everyone who is eligible to reapply has yet made a decision
         2. 2 spots open (one year term) due to members stepping down
         3. Anticipating at least 4-5 open spots will need to be filled
      2. New member applications have been distributed
         1. So far, only 1 application has been received
   2. Discussed outreach to past members, and also looking at who applied last year but were not selected
      1. Do we want to add permanent, non-voting members from various organizations that can provide vital expertise?
4. Public Comment
   1. Len: OCTF will be meeting with Jerry Foxhoven in June about aging & disability and is looking for a list of very specific questions for him to answer
      1. Send questions to Len – think of one thing you would like to ask – email by end of next week
   2. Harry: Proposed that there be a subcommittee to develop candidate questions for the governor election (and other candidates that the committee decides) related to disability issues; goal to have these answered and published; Len seconds; All approve; motion passes
      1. Kathleen sent a link to the RevUp voting campaign – there are suggestions for questions, with the suggestion that these be tailored to local issues
         1. ACTION ITEM: Caitlin will forward this out
      2. Len: DM Register has been reporting on the candidates as well
      3. Bruce, Kathleen, Len willing to work with Harry on this
   3. Roxanne: Attended Bottom Dollar event; it was excellent; Kay was one of the panelists
   4. Roxanne: CHIP funding is once again at risk of being cut; Epilepsy Foundation has sent out an action alert
   5. Harry: Has noticed that cars are parking and blocking curb cuts, and there is only a $15 fine for this; Harry brought this to the attention of City Council, and this is now being reviewed and they are considering raising the fine; it is important to look at this issue in local communities
   6. Roxanne: Serves on the Iowa Transportation Coordination Council (led by Iowa DOT); they are looking to increase attendees & members; Kristin Haar chairs that council
   7. Dawn: From Iowa Disability and Aging Advocates Network
      1. Dan Andersson from the MS Society working on home modification bill, but it went nowhere in this year’s legislative session
      2. Fuel Assistance bill also did not go anywhere
         1. Len – working in Davenport to change the ordinance there
      3. Opioid Bill success – Schedule V medications that are anti-consultants used for managing seizures were removed from the bill; this is good for ensuring access to these medications
      4. Bill to move people with serious long-term care needs out of MCOs and be managed by the state – did not pass by 1 vote
         1. Suggestion to send a letter to DHS to consider doing this anyway
         2. Debbie Johnson – IME has changed the case management system (state no longer has these services); keep in mind that the state does not have infrastructure at this moment to support this
         3. Len – suggests OCTF send thank you notes to those who voted in favor of this bill
            1. ACTION ITEM: Julie to look up who voted for the bill and ensure they get a thank you email
   8. Roxanne: Epilepsy Foundation funding was reinstated in the budget – but this is pending a signature by the Governor
   9. Rozanne: Via National Epilepsy Foundation – meeting with Medicaid directors on various issues
   10. Harry: Older Iowan Legislature summary of legislative session; IDA received $100k to collaborate with DHS on pilot long-term care initiative for non-Medicaid consumers who want to live in the community
5. Department of Human Services Update – Theresa Armstrong & Deb Johnson (by phone)
   1. Theresa
      1. Complex Service Needs (HF2426) has been signed and DHS is moving forward
         1. Requires some more core services to be provided, including Access Centers (including crisis residential and subacute), whole array of crisis services (mobile response, 23-hour observation, crisis residential and community supports), and ACT programs (currently 11 programs, legislation requires 22)
            1. Notes that the number of ACT programs almost doubled since the Regions have been in place (from 6 to 11)
         2. Administrative rules need to be developed to guide implementation
            1. Services need to be defined, provide guidance on access standards, implementation timeframes need to be developed and communicated
            2. Plan for July 2018 to have Rules be noticed by the MHDS Council and made publically available (legislation requires this happen by August)
         3. Regions are already working on their plans for implementation
         4. SAMHSA grant released – DHS will be developing a proposal and, if funded, will be working collaboratively with the Regions on this
         5. Some workgroups also included in the legislation – formulating what is required of the workgroup and who needs to be on them
            1. Will include tertiary care hospitals who manage the most complex needs patients (Cherokee and ? will be part of these)
         6. Many counties have signed on to the Stepping Up initiative – jail diversion focus; also many Regions using telehealth to provide MH services in the jails
      2. Children’s System EO was signed by the Governor
         1. Children’s Workgroup has been operating for several years, but the workgroup did not have a recommendation due to the legislation this year (but this happened anyway!)
         2. Governor has directed, using recommendations from the workgroup, the development of a Board with specific requirements for memberships of state agencies and other stakeholders and consumers
      3. Questions:
         1. Harry: Hearing many cases of MCOs refusing to pay for necessary medications prescribed by doctors, what can be done?
            1. Deb (Theresa asked Deb to respond): Is the drug on the PDL? If it is – then why isn’t it being paid? If it isn’t – what other drugs are available? Typically, if it is denied, it is usually an issue of lack of communication between provider and MCO; should call member services and grieve it
         2. Harry: Conflict of interest of case management – how can they be neutral
            1. Deb: When you think about it, case managers used to work for counties; their job is to advocate for the member; members should file a grievance if their case manager is not advocating for them; noted that case managers cannot authorize services, and this is the same as how it was handled when case managers worked for the counties
         3. Bruce: Seeing a little different approach under current system – example of a member whose needs were at the floor rate, but the MCO approached Bruce to ask to reduce the rate; later the case manager went to the member’s home with a provider and informed the member that they were moving them to a different provider because Bruce’s agency was unwilling to adjust the rate below the floor. There has been a rumor that case managers were offered financial incentives to reduce costs/services – but not sure if this is true.
            1. Deb: IME has heard the rumor as well and has brought it up with the MCOs; IME has discussed issues with MCOs about finding the balance to ensure people are getting the services they require (noted that there is history of overpayment and underpayment)
         4. Kay: Under the country system, they were not looking for a profit (although they were looking for savings); personal experience is that the case manager so far has been a positive experience; noted case manager takes recommendations to a review team, and this is concerning because the review team has never met the member; when we can’t good data, we can only rely on anecdotal stories
            1. Deb: There are things that are working and there are things that need to be improved on; there are a lot of rumors – so IME asks for the specific details; IME wants to know when there are problems because IME wants to hold the MCOs accountable; most of the time, when IME digs into the situation, the issue falls back to communication; noted that there is a budget that the system has to operate within to meet needs, and if this is not managed the entire Medicaid system is at risk
         5. Len: Len asked how people will conceive of another tier of decision makers for children when the MCOs and regions are already players. He asked what Theresa thinks of the feasibility of creating another system. Len said he was more concerned about the payment and nuts and bolts of this new system.
            1. Theresa: An issue is that we are very fragmented and siloed, and we currently don’t have a children’s system and there needs to be an overarching entity for children. She said the children’s wellbeing collaborative that have been functioning for a year are reporting the power in pulling people together around a table and really collaborating. Theresa said the logistics still need to be worked on, but all those separate agencies currently have some responsibilities for payment.
   2. Deb
      1. MCOs quarterly reports are out for review (they are online)
      2. AmeriGroup Member Choice was restored as of 5/1/18, so members now have a choice of MCOs, but changes can only be made during open enrollment
      3. Elderly Waiver and Children’s MH Waiver are being renewed this summer; opportunities for public comment will be available on the website
      4. Process Improvement Group has been established related to working with MCOs – information is on the website
         1. Has met three times so far and also meeting again today, with focus on process improvement
         2. Goal to make things better for everyone and making the system work more smoothly
      5. Working with MHDS on Complex Needs legislation that just passed, and will be collaborating on implementation
      6. Questions:
         1. Kay: 2nd Quarterly Report – cost savings did not include data point (but it was included in the 1st Quarterly report)
            1. Deb: There are concerns with accuracy of Encounter Data
         2. Len: Reports listed on MAC Website – are these the same reports? Is there any comparison work available?
            1. Deb: Same report; there is a delay on financial reports; some comparisons are available within the charts themselves; reporting reflects what is required by legislature
         3. Harry: MCO Watchdog Facebook site – article posted that indicated DHS will not vouch for Medicaid data; what is this about?
            1. Deb: Encounter data does not match what is in the fee-for-service system; states take several years to align the data systems; what is being reported is not yet at the “gold standard” of what is expected; also noted that data can interpreted in many different ways
6. Money Follows the Person Presentation – Brooke Lovelace
   1. Able to accept referrals until December 2019
   2. MCOs able to fund value-added services currently provided by MFP
   3. Little bit of money savings to serve people in the community – but that was not the goal of MFP
   4. Shared lessons learned
      1. Important for providers to be involved before the transition takes place
      2. Many individuals want to work when you start to have these conversations with them (many were not aware that this was even an option)
         1. However, seeing that many individuals are actually staying home (not even engaged in day programs)
   5. Senate File 227 / House File 5306 propose to reauthorize MFP
   6. Possibilities Newsletter – success story on Amos
   7. Developing a transition guide which will include lessons learned and what needs to be addressed before, during and after transition
   8. Questions:
      1. Tracy: Are you seeing more individuals with higher complex needs than when MFP started?
         1. Brooke: No. It has been fairly consistent. However, MFP has seen a difference in the population served. 2014 added the nursing home population (which includes individuals who were placed out of state). Serving more individuals with a brain injury.
      2. Bruce: Noted that the case loads are small, and this likely contributes to the success of the program. For out-of-state individuals, what does that look like from MFP’s point of view?
         1. Brooke: Transitioned 48 individuals through MFP. It is logistically challenging. 12 Transition Specialists each have a case load of 20-30 people who they follow for 365 days
      3. Len: How much money did Iowa get each year? What is the business case for keeping it? Thought this was a demonstration with the goal of the State picking this up?
         1. Brooke: $51 million when first awarded; $56 is what Iowa will end up spending (Federal and State dollars); the goal was that MFP was a demonstration program, and to demonstrate to the state what needs to be in place to keep this going; Iowa decided not to add some of these things to the waivers; there was thought that the MCOs would take over some of this
      4. Len (to John McCalley, AmeriGroup): Is there any financial incentive to the MCOs to engage in these activities?
         1. John:
            1. Contracts with the State include incentives to community-based providers to help facilitate moving members into the community
            2. 109 nursing home patients were transitioned without the use of MFP (some were not waiver eligible)
            3. Value-based contracting is the direction that managed care is headed
            4. Suggested an agenda item to bring MCOs and state reps together to discuss this further
      5. Kay: How many people took advantage of the College of Direct Supports?
         1. Brooke: 92 providers, and over 1000 individuals enrolled; does not have exact numbers
      6. Kay: How is complex needs defined?
         1. Brooke: Higher medical or behavioral support needs (e.g., 2:1 staff)
      7. Harry: Programs like this – we wait until they are in trouble with funding sources before we react? Should the Executive Committee draft a letter to the legislature?
         1. Dawn: A letter was sent; can resend this as well
      8. Tracy: MFP is specifically aligned with the OCTF. Concern is what we do to assure that these folks have a voice and an option? What might we be able to do to hold some accountability?
         1. Brooke: Keep as a standing agenda; monitor the number of individuals in facilities, how many have transitioned, are they staying in the community or returning to facilities
         2. Dawn: Noted that these questions have been asked, but the state has not been able to provide them.
            1. Brooke: MFP staff have access to these numbers.
         3. John: MCOs know how many people are in facilities; it’s part of the annual assessment regarding how many people are in facility-based or community-based services and supports; it is not clear how the Department stores this information or makes it available
         4. Len: Who at DHS is crunching these numbers and evaluating?
            1. Brooke: Unsure.
            2. Suggested this be a question during the June meeting with DHS
      9. Harry: Is there cooperation from the facilities?
         1. Brooke: For the most part, the facilities are very cooperative. The state made the decision to not close beds (as other states did). As people are moving out, those beds are filling.
      10. Bruce: Understanding that you have to be on ID/BI waivers to receive services?
          1. Brooke: There are not residential services included under the other waivers, which is why these are the two populations included under MFP
      11. Dawn: There are a lot of people out there who are not old enough to be on the elderly waiver and there are long waiting periods for the disability waiver – but these are folks who need supports with independent living. There is nowhere for these individuals to receive supports.
7. Medicaid Discussion
   1. Held a committee call earlier this week
      1. Last year, had wanted to meet with the three MCOs to discuss vision/mission and objectives. Have not yet met with United Healthcare. Going to try to get something set up for this.
      2. Kay shared about Parents for Care – started meeting last November; these were families who were impacted by the departure of AmeriHealth; the group has developed some priorities of things they would like to see changed, including a carve-out for this population, the way SIS is being implemented, real or perceived issues related to conflict free case management, and addressing workforce issues; they met with the Governor on Monday, she listened to the personal stories and seemed moved, but not expecting any change; spent time meeting with law makers during the legislative session; has done some outreach to IACP and DRI; trying to go statewide (mostly Des Moines right now)
      3. Committee is interested in feedback from the OCTF about how best to advocate and prioritize direction related to managed care (what are the next steps for the committee and how can we make an impact?)
         1. Without having Director Randal here, it is difficult to know what can be accomplished
         2. Len to report back to the committee after the meeting with Director Foxhoven
         3. Putting responses online to questions asked of candidates (or current politicians) is not partisan
      4. Roxanne will be rolling off the OCTF; Harry will need a new co-chair
         1. Bruce has agreed to stay on the committee even though he is also not going to remain on the OCTF
         2. Noted that anyone can be involved in committees, and they do not need to be members of the OCTF
         3. Kris Graves volunteered to join this committee.
8. State Agency Reports
   1. Kim Barber, Dept. for the Blind – Same funding level for FY19 as for FY18, pending Governor signature; IL services connected with 374 individuals across Iowa, 233 individuals have service plans in place, 141 were closed out (71% successful, 21% were ineligible, 12% incomplete such as for death/health issues/desire to not pursue); senior services specialists for the blind position was approved; 15% of funding focused on transition under WIOA – offered a transition teen retreat for students (14-21 years old) which was successful, planning the next retreat now; finished up IL senior orientation, which was integrated into orientation center in April; new teacher hired and will be based in the Western part of the state
      1. 800-362-2587 is the toll-free number – anyone can call
   2. Terri Rosonke, IFA – By Administrative Rule, HCBS rent subsidy requires that the person who owns the home cannot be a family member, IFA has received a request for an exception to policy related to this rule for two families who have purchase/adapted homes for their children (family is saying there was no option for housing in the community); IFA has responded that individuals who are renting from an immediate family member are assumed to not be at risk for losing housing completely, also granting this rent subsidy allows them to be eligible for HCBS waiver for life and this is not the intent of the rent subsidy; looking for feedback from OCTF related to the two cases discussed at the meeting – should IFA allow the acceptation to policy? Also noted that there are 173 people currently on the waiting list for the HCBS rent subsidy.
      1. Bruce: Sounds like, to get a Section 8 voucher, the parents cannot own the property and cannot get a waiver through Section 8.
      2. Len: If they are inclined, they don’t have to waive the rule completely but could put specific parameters around this. Parents can use a variety of other planning tools aside from the rent subsidy. It’s hard to justify keeping these individuals on the subsidy indefinitely, especially when there are so many people on the waiting list.
      3. Tracy: Parent has likely gone above and beyond to provide for their child to have a community-living option. There are lots of things we don’t know.
      4. Roxanne: Was not aware of the Federal rule that Section 8 requirements do not allow for renting from a family member.
      5. Dawn: Who can IFA refer the families to explore other options?
         1. Benefits or estate planner
         2. Options counselor at the Aging and Disability Resource Center
      6. Suggested that more information is needed from Terri
         1. ACTION ITEM: If OCTF members have thoughts, please share them; Executive Committee to respond to Terri
9. Taskforce Member Comment
   1. Jenna: Is a member of the United Spinal Association Iowa Chapter; another member contacted Jenna recently wondering if the OCTF could help create a position paper (or help with the legislative speak on writing a position paper) for the purposes of creating something to be sent to reps to share personal experiences related to Medicaid and personal attendant concerns
      1. Kay: IDAction has templates on the website for getting messages out
      2. Dawn: Would be happy to give feedback on anything that is drafted
      3. Len: National chapter likely also has resources
   2. Dawn: Independent Living received a Federal budget increase; $10 million in Part B and $2 million in Part C
10. Public Comment
    1. n/a

Thank you, Caitlin Owens!!!

The OCTF has made a donation of $176 to Shelter House in appreciation of your work for the OCTF. We wish you well with the new job and the new baby!