

OLMSTEAD CONSUMER TASKFORCE MEETING
December 7, 2018
10:00am – 3:00pm
Pleasant Hill Public Library, 5151 Maple Drive, Pleasant Hill
Conference Call-In: 888-290-7502, Participant Code 29273924#

MEETING NOTES

I. Welcome and Introductions

Taskforce members present: Alexandra Bomhoff, Mike Dierdorf (phone), Dawn Francis, Sean Goedken-Abramowitz, Heather Hanzlick, Tracy Kenniger, June Klein-Bacon (phone), Kay Marcel, Gary McDermott (phone), Kathleen O’Leary, Mary Roberts, Len Sandler, Renee Speh (phone)

Taskforce members absent: Jenna Battan, Randy Davis, Kris Graves, Derek Laney, Harry Olmstead

State agencies: Theresa Armstrong, MHDS, Connie Fanselow, MHDS, Terri Rosonke, Iowa Finance Authority, Ljerka Vasiljevic, Public Safety, Kim Barber, Dept. for the Blind

Guests: Linda Kellen (Inspections & Appeals), Brooke Lovelace (DD Council), John McCalley (AmeriGroup), Kinsey Poulos (Office of Ombudsman), Derrick Willis (CDD/UCEDD), Lisa Schneider, Dept. Human Rights- Client Assistance Program, Di Findley (Iowa Caregiver’s Association – phone)

CDD Staff Support: Anne Crotty, Julie Christensen

II. The Task Force observed a moment of silence in recognition of Pearl Harbor Day and the recent passing of Pres. George H.W. Bush.

III. Review, Additional Items, and Approval of the Agenda

Paula moved to approve the agenda. Mary seconded. No discussion. Motion passed (no nays or abstentions).

Agenda approved.

IV. Review, Corrections and Approval of the Minutes of the September Meeting

Len moved to approve the agenda. Kathleen seconded. No discussion. Motion passed (no nays or abstentions).

Minutes approved.

V. CDD Staffing Updates

Welcome Anne.

CDD transition – Julie & Derrick

VI. Letter of Support for Paralyzed Veterans of America grant

The group reviewed the letter of support, which was written by the Executive Committee. ICATER is the lead applicant. Easterseals Iowa (ESI) is also involved in this project, as is Kevin Dalin (former Task Force member). Videos will be produced through this project, and these will be available to everyone.

No concerns were noted by the Task Force.

VII. Iowa and Cannabis – Mary Roberts

Mary started a non profit organization (Families and Autism Advocates for Cannabis Treatment (FAACT) to advocate for the inclusion of individuals with autism in the list of qualifying conditions for Cannabidiol.

On Nov. 2, the Iowa Medical Cannabidiol Board voted to recommend that the state include Autism to the list of approved eligible conditions. Current eligible conditions include cancer, seizures, Crohn's disease, untreatable pain, MS, HIV/AIDS, ALS, Parkinson's and any terminal illness w/ <1yr life expectancy.

Mary shared two letters in support of this. (see attachments).

The next Iowa Board of Medicine meeting will be on December 13-14, which Mary will be attending.

Mary asked that the Task Force also submit a letter of support.

Len moved to approve sending a letter of support. Kathleen seconded.

Discussion:

- Paula noted that this provides people with disabilities an additional tool to make living in the community an option This is a good point to include in the letter.
- Sean asked what research is available regarding the positive impact of medical cannabis for individuals with autism. This is also a good point to include the letter.
 - **ACTION ITEM:**
 - **Mary will forward information about available research to the group.**
- Kay noted that there have been several articles in the DM Register recently. Kay shared a story about a family who has been notified by the provider that they will no longer be supported in an individual setting due to the insufficient reimbursement rates from the MCO.
- Heather commented that the development of a statement that can be used by families and self-advocates could be helpful when interacting with drug & alcohol substance abuse counselors. Heather would love to work on this with other members of the Task Force. Additionally, from a multicultural perspective, there is need for more research

related to the impact on different populations. It may be helpful to work with tribes that may have used marijuana for ceremonial or medicinal purposes.

- Mary shared the concern that there are multiple psychotropic drugs that are legal to provide to individuals with autism, but medical cannabis is not currently allowed (yet there have been no reported deaths as a result of using it).
- Mari asked if there is any movement around education and outreach to medical providers on this topic?
 - Mary noted that IDPH has reported that it is very difficult to find medical providers who will prescribe CBD oil and insurance does not cover it.
- Mary shared that a photo ID is required to pick up CBD oil, but you can call IDPH to apply for a waiver if it is difficult for the person using CBD oil to obtain a state ID.
- Heather noted the need to connect to other diversion initiatives across the states. There are many young people, especially young people of color, that are self-medicating.
- Paula asked if there are other committees working on this issue from an advocacy perspective, which the Task Force might connect with around this issue.
- Mary shared that Families and Autism Advocates for Cannabis Treatment, Autism Society of Iowa, and the Iowa Chapter of Mothers Advocating Medical Marijuana for Autism are also supporting this effort.
- Alexandra mentioned that privacy is a concern when there are several individuals living together in a congregate care model. Sometimes individuals are hospitalized for longer than needed, which increases the cost of care.
- Len shared that IDPH has put out multiple resources on this topic that are easily available online.

Motion passed (no nays or abstentions).

VIII. **DHS / IME Updates** – Theresa Armstrong

Update on Legislative Reports that are being submitted to the General Assembly in advance of the upcoming legislative session:

- Senate File 504 (report posted on the DHS website on September 3)
 - This Senate File required the regions to develop local community plans, to spend down balances; and to report outcomes; and for DHS to develop a Complex Services Work Group.
 - All MHDS regions submitted reports in Oct. 2017; they moved forward on what they had in their plans
 - Theresa noted that the regions' plans aligned well with the recommendations of the Complex Services Work Group.
 - Regions noted that the process of reporting outcomes was beneficial in opening the doors of communication with the jails and hospitals.
 - Tracy inquired what the barriers to collecting data have been.
 - Theresa noted that definitions have been difficult to navigate

- House File 2456 Complex Support Services
 - Calls for the development in the regions of Assertive Community Treatment Teams (ACT), access centers, comprehensive community-based services, and sub-acute and intensive residential service homes.
 - All regions are actively working on planning now.
- - 5 developing (meaning there are dates and milestones set); 8 regions planning for access centers
 - 11 ACT teams currently covering 33 counties, with an additional 11 teams in development.
 - 41 counties w/ mobile response teams (8 regions); 3 regions planning; additional counties are planning.
 - 23 hour holding and observation: 50 beds, 3 in development, 8 regions have access.
 - Community based crisis stabilization: 2 counties in development
 - Crisis stabilization residential: 85 beds, 19 in development
 - Sub-acute – 10 regions actively planning 9 beds, 16 in development, 3 facilities submitted letters of intent to be licensed
 - Intensive residential services homes – 1 Region developing, 9 planning
 - Access centers and intensive residential service homes must have crisis stabilization, care coordination, and not eject or reject consumers. They must instead develop skills in the workforce to manage behaviors.
- DHS developed rules for all of these services, as well as access guidelines.
 - These rules were adopted by the MHDS Commission yesterday and they go into effect on March 1, 2019.
- Tertiary Care Work Group (Psychiatric Intensive Care)
 - Work group released their report on Sept. 30.
 - This group is addressing the need for intensive inpatient psychiatric care and in-patient services for individuals when the regular acute care services are not working.
- Children’s Mental Health System strategic plan
 - Submitted Nov. 15.
 - This group looked at the development of a children’s system (0-18), with universal screening related to behavioral health, and consistent core services identified.
 - Local governing (MHDS Regions) is the recommendation for the governing body of the system.
 - Timeline:
 - By July 2020, screenings will be provided for all children.
 - By July 2020 crisis services will be available.

- By July 2020, a system of care concept will be used,
- By October 2020, eliminate the CMH waiver waitlist and expand the system of care statewide.

Discussion:

- Paula asked if all regions utilize the same eligibility criteria.
 - Theresa explained that eligibility is outlined in the Rules (Chapter 25), not noted that assessments are local.
- Sean shared how difficult it is to find, train and keep consistent staff in intensive settings, and wondered whether the reimbursement rates are high enough to support these services. Sean also expressed concerns with co-locating individuals with serious behavioral needs, and wondered if there is an opportunity for a higher reimbursement rate if a higher individualized level of supports are needed.
 - Theresa noted that these individuals are eligible for the highest tier in habilitation or ID waiver; but that rate may be a challenge for some individuals. Regions will work with the MCOs on this issue. Individual situations would be addressed through the regions & MCOs and may be addressed through an Exception to Policy.
- Kay noted that there is perhaps a flaw in the model, as individuals with significant behavioral concerns tend to do better in individualized or smaller settings. The congregate model is done to control cost, but there may be an impact on individuals in terms of increasing incidents and crises.
 - Mary inquired whether there are models from other states that have looked to address this.
 - Sean will monitor issue to determine how the Taskforce can support providers.
 - Theresa noted that there are already some models within Iowa.
- Renee asked about how CMH waiver capacity and challenges with workforce
 - Theresa noted that workforce is a challenge, and it was discussed by the Board but not addressed within the recommendations.

IX. Setting 2019 Meeting Schedule

- The group discussed whether to keep the existing schedule (beginning in January) or to have the next meeting in February due to today's meeting being rescheduled.

- The group felt that meeting in January would be beneficial for the purposes of setting legislative priorities. Continuing every other month, on the 2nd Friday of the month, the schedule would be:
 - January 11
 - March 8
 - May 10
 - July 12
 - September 13
 - November 8

Kay moved that the Task adopt the 2019 meeting schedule as discussed. Paula seconded. No discussion.

Motion passed (no nays or abstentions).

Action item:

- Anne/Julie to send the meeting schedule out to the group.

X. Taskforce Committee Reports

- A. Executive Committee Report
No report
- B. Medicaid Committee Report
No report
- C. Olmstead Plan Committee Report
No report
- D. Community Access Committee Report
No report

XI. State Agency Reports

- Kim (DOB) - Dept. of the Blind made a \$2.5 million budget request for the upcoming fiscal year (\$80k increase from last year) with the goal of adding a 6th independent living teacher
 - Noted that the State appropriation has declined. There were 9 teachers in 2012, but the number dropped to 4 in 2017. This decreased in support resulted in an increased time between visits to 6+ weeks.

Discussion:

- Dawn asked whether the drive time is a challenge since there are only 5 teachers currently covering the state.
 - Kim agreed that this is a factor in the time between sites. Most teachers spend about half of their time traveling from one location to another.
- Teri (Iowa Finance Authority)

- The HCBS Rent Subsidy Program encouraged new applications to be submitted from persons with disabilities receiving services under a Medicaid Waiver who are paying more than 30% of their income toward rent and might qualify for rental assistance. There are now 340 approved participants in the HCBS Rent Subsidy Program, with 107 of those participants having been added to the program since July 1. There are currently 56 applicants on the waiting list.
 - Analysis of impediments to fair housing is in final stages of development. They received adequate feedback from the statewide survey.

XII. Taskforce Member Reports

- Dawn – reminded the group that open enrollment for health insurance is open until Dec. 15, and it is not being well advertised, Please help to get the word out.
 - **ACTION ITEM:**
 - Please be thinking about legislative priorities for the Task Force between now and the Jan. 11 meeting.
- Len – Sent an email re: the unified state rules for seclusion and restraints in schools. Len read the draft rules to the group. A fact sheet will be put together on this. The Board will approve and publish the new rules for public comment. The group worked on defining what is considered a reasonable scenario for the up of seclusion and restraints.
 - Mary asked if parents impacted were involved in the work group. Mary also thanked the group for including BOTH seclusion and restraints, as restraints are often left out of the conversation but are equally potentially harmful.
 - Len shared that parents were not specifically part of the group, but many members of the groups shared stories and experiences to ensure that perspective was captured.
 - Mari shared that ASK Resource Center receives a lot of calls about this issue, so is grateful that this is moving forward.
 - **ACTION ITEMS:**
 - Anne/Julie to forward the email, with the draft rules, to the updated distribution list. Feel free to circulate this information with others.
 - Please review and provide feedback to Len to share with the work group.
 - Len will keep the group updated as to when the rules are published and open for public comment.
- Paula – noted the Des Moines Register piece on elder abuse, which was written by Len, and shared her personal experience,
 - Len noted that the College of Public Health was a partner on this piece.
 - Kay – Iowa Parents for People is an informal group of parents of adult children who share concerns regarding what is happening to services under managed care. The group now has a Facebook Page. The group is for siblings as well. The group is started to identify legislative priorities for the coming year, which will focus on addressing case management stability and decrease in funded services & supports. Link: <https://www.facebook.com/groups/IowaParentsforPeople/>
 - Mary asked if the group meets in person or online? And is there an email list?

- Kay shared that there was an in-person meeting, but this is difficult. There is an email list
 - Kay also mentioned concerns that the current
 - **ACTION ITEM:**
 - Website is out of date, but Kevin Dalin will work with Anne on getting this updated.
- Mary – Tracy and Mary were planning to meet with DRI regarding the 7.5 hour issue, as discussed at a previous last meeting. Mary wondered whether this is still an issue/priority for the group?
 - Tracy added that individual situations need to be referred to DRI to be looked at and investigated.
 - Paula noted that this issue could be taken to the Oversight Committee and shared as part of the public comment section of their meeting. The Medicaid Advisory Committee is another potential avenue to explore.
 - Kay noted that the 2nd meeting of the year is next week. She also suggested that the comments be submitted in writing.
 - **ACTION ITEM:**
 - Mary will draft an email, and forward to Anne for distribution to the group.
- Heather – App called Vitals is open to individuals with disabilities that allows them to describe what they need in an emergency situation.
- Paula – Together We Can Conference will be Saturday, May 4. There will be a strand for self-advocates, and financial assistance is available.
 - Dawn expanded that the Heartland Self Advocates Regional Network (HSRN) will be offering a follow up conference as well during May 31 – June 2 in Independence, MO. There is interest in identifying self-advocates who will commit to attending both. These individuals will need to agree to be part of follow-up, in an effort to create a leadership network within the state. Funding will pay for food, travel, and personal assistance services as needed.

XIII. Public Comment

- Brooke Lovelace (DD Council) – Wondered if the Autism Society of Iowa has submitted a letter of support related to the medical cannabis initiative? Also, the 99-county sweep will start the beginning of the year, please let Brooke know if you'd like to host in your county.
 - Mary noted that the Autism Society of Iowa approved unanimously to provide a letter. Autism Speaks and the Iowa Regional Autism Assistance Program declined to write a letter of support, citing a need for more research (per follow-up with Mary).
 -
- John McCally (AmeriGroup) – Noted an increase in demand for consumer options. However, there is a shortage of independent brokers in Iowa. Please access your networks to find potential brokers. Veridian CCO web page has additional information and resources.
 - Mary asked whether the MCOs would consider hiring folks to serve in this role.
 - John noted that the Federal Code requires that these be individual brokers. They must also be an Iowa Resident, register with IME, and go through an online training.

- **ACTION ITEM:**
 - John will provide an ISB “blurb” to share with the group (will send to Anne/Julie to send out to the larger group)

- Di Findley, Iowa Caregivers Association (via phone) – Advocating for the Future Ready Iowa bill to include the direct care workforce.
- Heather Strachen, NAMI (via email) – NAMI has a new Director of the Iowa Office of Consumer Affairs (OCA), Emily Berry. Her position now focuses on the OCA and the U of Iowa Peer Support Training Collaborative. Emily will be able to give the OCA the greater attention to outreach that it needs and deserves. Heather is remaining as NAMI’s Program Manager and directing a new federal grant project for NAMI.

XIV. **Adjournment**

Meeting adjourned at 1:46pm

Next Meeting: Friday, January 11, 2019