

**OLMSTEAD CONSUMER TASKFORCE MEETING**  
**September 9, 2014**  
**Pleasant Hill Public Library, 5151 Maple Drive, Pleasant Hill**

**MINUTES**

Handouts

Agenda

Minutes of Previous Meeting – July 11, 2014

Executive Committee Minutes – September 3, 2014

Letter to Iowa Economic Development Authority providing Taskforce comments on Five Year Consolidated Plan – August 13, 2014

Taskforce comments on LIHTC Qualified Allocation Plan – September 9, 2014

Taskforce comments to Iowa Insurance Division on streamlined prior authorization – September 3, 2014

Response from Senator Grassley to Olmstead Taskforce communication regarding U.N. Convention on the Rights of Persons with Disabilities

**Taskforce Members Present:** Joan Bruhn; Roxanne Cogil; Jackie Dieckmann; Ann Gallagher; Tracy Keninger; June Klein; Ashlea Lantz; Geoff Lauer; Michele Meadors (by phone); Linda Moore (by phone); Kathleen O’Leary; Mary Roberts; Len Sandler; Bruce Teague (by phone); Jennifer Wolff

**Taskforce Members Absent:** Paula Connolly; Carrie England; Gary McDermott; Rik Shannon; Jenn Wolff

**State Agency Representatives Present:** Theresa Armstrong and Karen Hyatt-Smith (DHS – MHDS); Kristin Haar (DOT); Deb Johnson (DHS - IME); Kristin Haar (IDOT); Terri Rosonke (IFA)

**Staff:** Bob Bacon; Liz O’Hara

**Guests:** Cherie Clark (by phone); Dawn Francis; Jane Hudson and Disability Rights Iowa staff (Whitney Driscoll; Linda Firkins; Christie Gerken; Kelly Gibbs; Jayna Graherholz; Char Joens; Mistie Johnson; Nathan Kirstein; Mark Leamen; Scott Lyon; Cindy Miller; Hope Richardson; Beth Rydberg; Emmanuel Smith

**I. Welcome and Introductions**

Chair Geoff Lauer opened the meeting at 10:10 am with a welcome and introductions. A quorum was declared. New Taskforce member Ann Gallagher, attending in person for the first time, shared information about herself.

Liz O'Hara made a brief announcement that CDD has secured staff support to update the Taskforce website ([www.olmsteadrealchoicesia.org](http://www.olmsteadrealchoicesia.org)) and that member suggestions about posting additional information can now be accommodated.

## **II. Review, Additional Items, and Request for Approval of the Agenda**

June Klein asked that action be taken now to approve the Systems Advocacy and Organizational Advocacy Awards to be made later in the meeting. Roxanne Cogil moved that the agenda be approved as revised. Len Sandler supported the motion. Motion carried.

### **Nomination Committee Report**

Moved by Kathleen O'Leary and supported by Roxanne Cogil to approve the resolution (attached) awarding the 2014 Ray Gerke Systems Advocacy Award to Cherie Clark. Motion carried unanimously. Moved by June Klein and supported by Mary Roberts to approve the resolution (attached) awarding the 2014 Organizational Advocacy Award to Disability Rights Iowa. Motion carried with Ann Gallagher abstaining.

## **III. Review, Corrections and Approval of the Minutes of the Previous Meeting – July 11, 2014**

Moved by Linda Moore and supported by Len Sandler to approve the minutes of July 11, 2014. Geoff wanted to make note of Jane Hudson's comment, during the discussion of the new CMS rule on integrated settings, that the State Resource Centers are in violation of Olmstead. Motion carried.

## **IV. Executive Committee Report**

- A. Iowa Economic Development Authority Five Year Consolidated Plan for Housing and Community Development. The period for public comment on the needs assessment phase of Plan development ended August 13<sup>th</sup>. The Executive Committee submitted comments. The two main points were (1) that the Authority needs to bring its policies and programs in line with what other state agencies are doing to create employment options for people with disabilities (e.g., prioritizing community development block grant (CDBG) funding to support job training for people with disabilities); and (2) that EDA's housing and CDBG resources can and should more generally target people with disabilities. Moved by Len Sandler and supported by Roxanne Cogil to endorse the Taskforce comments on the needs assessment for the drafting of the Five Year Consolidated Plan. Motion carried.
- B. Iowa Finance Authority Low Income Housing Tax Credit Qualified Allocation Plan. Michele Meadors and Liz attended the IFA public hearing on the 2015 Low Income Housing Tax Credit Qualified Allocation Plan (LIHTC QAP). As

Michele had not yet arrived at the meeting, Liz reported that Michele had presented IFA with comments on the Plan approved by the Executive Committee, and had made two comments in the course of the hearing. One hearing attendee had protested the new requirement that accessible units be scattered throughout a project, stating that it was easier to confine accessible units to one area. Michele had pointed out that people with disabilities don't want to feel segregated in this way. She also thanked IFA at the end of the hearing for its responsiveness to disability issues and its continuing effort to encourage compliance with Olmstead principles in its funding decisions.

Jackie Dieckmann said there are good reasons to house some people with disabilities close to each other, with access to the supports they need. People feel a part of their community. For example, many people with mental illness have trouble getting transportation. She does support separate, individual units for people. Geoff said the Olmstead decision doesn't prohibit this model; it should be a matter of choice. Len said transportation issues should be dealt with through zoning and planning. He described a congregate housing project in Dubuque, created by people with disabilities, which had universal design features. No one wanted to live there—"a big lesson" for people who thought this kind of community would be desirable. Len asked what the distinction might be between congregated housing, and units in an apartment building that is close to services.

Jackie cited apartment buildings in Nebraska with independent units but using a clubhouse model that offers access to services such as supported employment and volunteer opportunities. This is helpful for people with chronic mental illness who often feel isolated, though Jackie acknowledged the model may not be for everyone. Dawn Francis pointed out that the clubhouse model is not residential; Liz said that questions have been raised for several years about how supportive housing can be consistent with emerging policies on integrated settings. Jackie said access to key services such as transportation and nutrition is key. June noted that this model touches on the work of all Taskforce committees--transportation, housing, etc.

Moved by Tracy Keninger and supported by June Klein to endorse the Taskforce comments on the Iowa Finance Authority's Low Income Housing Tax Credit Qualified Allocation Plan. Motion carried.

- C. HF 2463 – Streamlining Prior Authorization Process for Non-Formulary Medications. Roxanne Cogil provided an update on developments since passage of HF 2463, which includes provision to streamline the prior authorization process for drugs not on an insurance carrier's approved list. The law includes a requirement that the insurance company would have to act on the request within 72 hours. This would greatly benefit people with epilepsy, mental illness and other chronic conditions who may require frequent changes in medication. Insurance companies have resisted this

deadline, arguing instead for a 15 day turnaround. Roxanne reported that there was overwhelming support at an Insurance Bureau hearing for retaining the 72 hour deadline. The Executive Committee responded to an urgent call for advocate support, providing comments on September 3, 2014. Roxanne expected rules to be posted by Wednesday 9/17. Moved by Len Sandler and supported by Roxanne to endorse the Taskforce comments on streamlining the prior authorization process for non-formulary medications submitted to the Insurance Bureau on September 3, 2014. Motion carried.

- D. U.N. Convention on the Rights of Person with Disabilities (CRPD) – Response from Senator Grassley to Olmstead Communication. Geoff reported that he had recently received the response distributed to Taskforce members, in which Senator Grassley explained his continuing opposition to the CRPD. Dawn Francis expressed disappointment, reporting that she and other advocates had met with Senator Grassley during the annual National Council for Independent Living conference in July, and had tried to respond to all of his concerns. Bob Bacon said it is his understanding that two Republican Senators have changed positions due to some amendments.

Geoff also reported that he had received Senator Harkin's report on barriers to self-sufficiency faced by people with disabilities, and it is clear that the Taskforce priorities are well aligned with the work Senator Harkin is doing in this area.

## **V. Nominations Committee Report**

- A. Announcement of 2014 Ray Gerke systems Advocacy Award Winner – Cherie Clark. Cherie Clark was present by phone. June Klein read the resolution adopted earlier in the meeting, citing Cherie's dedication to empowerment of people with disabilities. As a person with lifelong disability experience, Cherie used her skills in grassroots organizing to establish Peer Action Disability Support, which has worked successfully for systems change in public transportation and accessibility of public buildings and facilities. PADS has also conducted voter education activities, and has spoken out on state and even some federal issues. Cherie said she was honored to receive the award, and that she knew Ray Gerke for many years. In her 40 years of advocacy she has seen a lot of progress, especially with the passage of the Americans with Disabilities Act, but a lot of work remains to be done, especially in the areas of housing and transportation. She noted that she sits on the Non Emergency Medical Transportation Advisory Council, which had met the previous day. She is deeply concerned about the operation of the transportation brokerage, and stated that we all need to ensure that people on Medicaid have access to the healthcare benefits to which they are entitled. She went on to say that as a young woman she was very shy, but with help from mentors she learned to stand up for herself and become an activist. She encouraged each Taskforce member to do the same. She concluded by saying that the disability community must find ways to unite for progress.

Geoff stated that he anticipated being able to present Cherie with her award in person on September 26<sup>th</sup>, in Cedar Rapids.

- B. Announcement of 2014 Organizational Advocacy Award – Disability Rights Iowa. Geoff announced that the Taskforce was making its first organizational advocacy award in 2014, to Disability Rights Iowa. He asked Executive Director Jane Hudson to introduce the DRI staff members present. Much of the work responsibilities staff people described relate to *Olmstead* issues. Geoff read the resolution passed earlier in the meeting, and thanked DRI for working on these issues conscientiously, including the treatment of youth in institutional settings, and for being a reliable resource for families. Jane Hudson said the recognition was welcome, particularly since so often she and her staff find themselves in adversarial positions. She acknowledged the overlapping missions of DRI and the Taskforce.

## **VI. MHDS Redesign Committee Report**

- A. Clarification of committee focus. June Klein said so many service issues had come before the new committee that it had tried to clarify its focus, in order to align closely with the mission of *Olmstead* compliance, and to aim for the most impact from committee activities. The focus will be on service gaps caused in some way by MHDS redesign and by the rollout of the Integrated Health Homes (IHH) Initiative. Geoff said he does not want important service issues such as those being experienced by Consumer Choices Option families to be ignored, but they are not in the committee's scope.
- B. Update on OCTF Integrated Health Homes Survey. June reported that the survey the MHDS Redesign Committee had developed to collect information on people's experiences with IHH had been of interest to many organizations, who assisted in its dissemination. She has had 240 responses to date, reflecting varied satisfaction levels. The survey will close on 9/30/14. Geoff will assist June with the analysis of responses and the creation of a report. June said that survey results are of interest for quality assurance purposes to both Magellan and to the MHDS Division. Geoff said that State Senate President Pam Jochum expressed interest in the survey report. He cautioned that survey results will be anecdotal and cannot be generalized.

Jackie Dieckmann commented that it may take a year for the IHH initiative to be fully developed; she still does not know the services to which her son will be entitled. June reported that Magellan sent the survey out, but will also probably do a follow up survey later when the IHHs were more mature. Dawn Francis said that she has heard complaints from providers about reimbursements. June said she has received some responses from providers. Geoff said that the Iowa Association of Community Providers could probably assist the Taskforce in reaching its members.

Taskforce members shared anecdotes of hard-to-serve consumers, especially those with co-occurring mental illness and substance abuse issues, whose lives are so unstable that the service system cannot respond adequately. They burn bridges with providers and frequently land in jail for lack of other options. DRI is gathering information on incarceration of people with mental illness. Bob Bacon mentioned the Substance Abuse and Mental Health Services Administration's new Housing First service model, based on the recognition of the importance of a stable place to live for people with co-occurring disorders before services can be effective. Information is available through a SAMHSA webinar. Karen Hyatt added that even if people are housed, they still need to be well enough to access services; June said this has been mentioned in discussions of jail diversion programs.

- C. Gap in Children's Mental Health Services. June said she has learned from conversations with parent-advocates that there is a lack of step down services for children discharged from Psychiatric Medical Institutes for Children (PMICs) or from out-of-state facilities. Parents are not equipped to care for their children at home, and the only way they can get what they need is through the Child in Need of Assistance (CINA) process. Group homes could provide step down services but children cannot receive Children's Mental Health Waiver services in group homes. The issue was mentioned at a recent MHDS Commission meeting. The Committee is trying to determine if the remedy would have to be a change in Code, or if it is a matter of the way the rules are being interpreted. Rick Shults and a representative from NAMI's Children's Mental Health Committee have been asked to join in a discussion.

Len Sandler said that he was asked by his MHDS Region to make a presentation in November on the relationship between residential care facilities (RCFs) and the *Olmstead* decision, and also to talk about the future of RCFs. June Klein said the core issue is what the regions can legally and appropriately pay for.

## **VII. Transportation Committee Report**

- A. Advocacy for Inclusion of NEMT as an I-HAWP Covered Service. The Centers for Medicare and Medicaid Services (CMS) approved a waiver of Non Emergency Medical Transportation services from Iowa's expanded Medicaid program (I-HAWP) for only one year, ending 12/31/14. Continuation of this waiver would be determined by CMS based on an assessment of its impact on the service delivery system. Iowa is requesting an extension of the waiver. There is a deadline for public comment, on 10/13/14. The Taskforce has consistently expressed opposition to the NEMT Waiver. Geoff asked for a motion to authorize the Executive Committee to draft a letter reiterating the Taskforce position to DHS. This was so moved by Michele Meadors and supported by Roxanne Cogil. Motion carried. The Taskforce discussed the need to communicate with CMS on this issue as well. Moved by Len Sandler

and supported by Michele Meadors to authorize the Executive Committee to convey the Taskforce opposition to extension of the NEMT waiver to CMS. Motion carried.

- B. NEMT Transportation Brokerage RFP. DHS has also issued an RFP for a new contract for operation of the NEMT brokerage service. The RFP seems to suggest that DHS wants to see improvements in service quality.

## **VIII. MHDS/Redesign Update**

Theresa Armstrong, Bureau Chief, Community Services and Planning, provided the update, beginning with the request from the Executive Committee for an update on implementation of outcomes measurement in MHDS redesign. She reminded Taskforce members that an Outcomes Workgroup co-chaired by Bob Bacon, of which Geoff Lauer was a member, was charged with identification of key outcome domains. These included such areas as access to services, quality of life and safety, and family and natural supports. The idea behind outcomes measurement is to determine how people's lives are—or are not—better under the system and to get insights in how to make improvements. The workgroup also identified data sources, including claims data, provider surveys and family and consumer surveys. DHS will start by looking at billing data, which is available on a regional basis, to begin to measure service penetration rates, inpatient hospitalization usage (which the State wants to reduce over time), intermediate care facility utilization, mental health service utilization, supported community living, and the hours of service people received. Service costs per person and administrative costs will be tracked.

The provider surveys will generate information in such areas as the number of individuals employed, their hours worked and wages; the number in integrated housing settings, and information about person centered planning. Geoff asked for the timeframe for completing work on the reporting system. Theresa said there had been a setback with the loss of the staff person hired to do much of the work. Hiring his replacement is expected to take several months. She hoped to have the system fully operational in FY 2016. Bob commented that this "Quality Improvement Analyst" needs to have strong IT skills and a background in data analysis. Theresa said the person also needs to be able to translate the data into an understandable report on the performance of the system.

Len asked what measures will be used in concluding whether a person's ability to live independently has improved. Someone may have benefited enough from services to leave the treatment facility but may still be unable to get a job. Theresa responded that assessments need to look at multiple aspects of a person's life. Iowa is still developing its performance measurement system—e.g., an unanswered question is how to mesh Medicaid and non-Medicaid data. The ultimate goal is creation of a data dashboard accessible to the public that

would show the service gaps and where improvement is needed. Bob Bacon said it should also be possible to compare regions to look for ways to improve.

Theresa provided an update on crisis services and mechanisms for accreditation of providers. Only two crisis services are currently required in each region (24-hour emergency crisis services, and crisis evaluation and assessment, but all but one region expects to expand the scope of services beyond these.

Dawn Francis commented that although redesign was intended to make services available across Iowa in a more equitable fashion, clearly some regions offer more services than others. Theresa responded that Code now requires core services be available throughout the state; other core services will be established over time as funding permits. Geoff said some regions seem more confident than others of their ability to provide services. He thinks the Olmstead Taskforce and the Iowa Disability and Aging Advocacy Network (IDAAN) should advocate for expansion of services. He noted that in its last session the Legislature called for establishment of a work group to look at home and community based services for people with serious mental illness. The group is to be composed of consumers/family members, provider, several state agencies, and housing and employment representatives. The final report will be due in December.

## **IX. Iowa Medicaid Enterprise Update**

Deb Johnson, Bureau Chief of Long Term Care, said it would be helpful for her to have regular time on Taskforce agendas to provide updates on Medicaid.

Transition to Compliance with Integrated Settings Rule. Deb reported that IME held a series of public forums to take comments and questions on the new rule, prior to submitting its Transition Plan to accompany Iowa's application for renewal of the Intellectual Disabilities (ID) Waiver. There were more questions than comments from stakeholders, especially about what the rules mean, and many could not be answered until CMS provides more guidance to states. Deb said the most recent clarifications sent by CMS in the previous week were not very helpful. The Statewide Plan covering the rest of the Waivers is due to CMS in December. Deb continues to welcome any comments, but she is not likely to be able to set up as many listening sessions as she has in the past few months. She will try to respond to requests for them. IME held six such sessions; participation varied widely. Paula Connolly had asked for a webinar. Deb emphasized again that she welcomed input. This can still be provided on the IME website. There is a lot of confusion about this transition. Deb stressed it is not a matter of IME forcing these changes on Medicaid providers and stakeholders; rather, it is a matter of what IME can pay for out of Medicaid.

Dawn suggested Iowa should have just one waiver. Deb responded that this takes legislation action, and it would also take time to implement. The service package and related costs would have to be debated and decided. IME actually

began to work on integration of waivers, starting with the current Disability and Health along with the Physical Disabilities Waiver. Len pointed out that a Legislative Study Committee could be established to look at the issues

New agency staff. Sally Odekirk has been hired to replace Sue Stairs, working on the Disability and Health, Physical Disability and HIV/AIDS Waivers and will also work with hospice services.

HCBS Waivers. Based on the increase in legislative appropriations in the last session, IME has begun giving out additional waiver slots. As expected, there is a 40 – 50% uptake on the waivers, meaning that by the time people on the waiting list are contacted about availability, half of them tend to no longer be seeking a slot for various reasons. She expected it to take a year to spend the \$6 million increase in funding; limiting factors include a lack of case managers and social workers. Michele Meadors commented that people who have been on the waiting list for some time need to make sure their contact information is current. Deb agreed, saying IME's return mail in these situations is "huge." Some people have been on the waiting list since 2012. People waiting for the Physical Disability (PD) or Disability and Health Waivers tend to have to wait the longest. Len asked if IME has data on why people go off the waiting list; Deb says the data are there but not readily available. If someone goes off the list IME tries to hold his/her place on the list for a while, to accommodate temporary situations. Michele said this is another reason for good communication with IME.

Core Standardized Assessment Implementation. Deb reported that implementation of the Supports Intensity Scale (SIS) assessment for people with ID, by IME's contractor, Telligon, has been underway since August. Things may speed up in the future as Iowa moves towards resource allocation. IME is watching other states' experience closely. Geoff asked the status of work on the Brain Injury assessment tool. Deb said that DHS will host a meeting with the Brain Injury Advisory Council and the Brain Injury Alliance to discuss the results of listening sessions on BI assessment tools. There are not many available, although Deb suspects more will be developed because of the emphasis on Core Standardized Assessments under the Balancing Incentives Program (BIP). Deb said it was possible that tools might change over time.

Consumer Choices Option Issues. Mary Roberts brought up problems in communications between DHS and families using the CCO option. There is a great deal of confusion about CCO requirements, and Mary said that families are running into problems despite their best efforts to comply with program regulations. Deb asked for suggestions to improve communications. A webinar is one possible tactic. Mary said she would be happy to share any helpful information with CCO families. Deb said that IME would need to send the information to Veridian Credit Union, which provides CCO financial management services, so that they can appropriately communicate with consumers. Mary said

that she would nevertheless like to find ways to collaborate with IME, as would Jim Paprocki, a CCO Independent Support Broker (ISB).

Mary asked for clarification on a new IRS ruling, effective in January this year, under which caregivers living with consumers are no longer obligated to pay income taxes on service earnings. Mary quoted an ISB as saying he had been told the rule only applies to an individual's sole care provider. Deb Johnson said that she did not know the terms of the new rule. An individual can only be paid for 40 hours of direct support under CCO. Mary said that individuals may need more than 40 hours and would have more than one provider. Len suggested that the Department of Revenue be asked if state laws affect the IRS ruling.

Deb said that she would talk to Acting Medicaid Director Julie Lovelady and to Brian Wines, who oversees CCO, about setting up a taskforce. Jackie Dieckmann said she is also interested in these issues as a parent. Geoff said that if there is an opportunity for Taskforce representation on workgroups, it is taken up by the Executive Committee.

## **X. State Agency Reports**

Department of Transportation. Kristin Haar reported that there is a community transportation study about commuter issues on I-380. She encouraged anyone interested to attend the hearings. Roxanne Cogil asked who had replaced Angela O'Brien, Statewide Mobility Manager. Kristen said the position no longer exists as a separate FTE. Jeremy Johnson Miller, DOT's Transit Program Administrator, now serves as the Statewide Mobility Coordinator. Ellye Kovner is the Polk County Mobility Coordinator. Roxanne asked that Kristin send information on Ellye and Jeremy to Liz O'Hara, to pass on to the Taskforce. Michele asked if Kristin could encourage Ellye to participate in the Transportation Advisory Group; Kristin will do so.

Iowa Finance Authority. Terri Rosonke reported that the annual HousingIowa conference the previous week was the largest ever, with 570 attendees. Len Sandler was a presenter. Next year the conference will be in Coralville. Terri said she is IFA's representative to the new workgroup, established under HF 2463, to study HCBS services for people with chronic mental illness.

The HCBS Waiver Rent Subsidy Program completed an end-of-year report. The program served 499 people in total, and an average of 333 people per month, with an average monthly subsidy of \$159.32. Since the program was opened up to new applications in February, 145 new participants were added. There are 104 people on the waiting list—not as many as Terri expected. She said that the program takes a conservative approach to adding new participants, for fear of running out of money, which puts the Authority in the position of having to use its own funds to keep the program running.

The comments received on the LIHTC Qualified Allocation Plan, discussed earlier in the meeting, are being reviewed by staff. There will be a response to each comment. Many were received on the points to be awarded to proposed projects close to public transportation, and to requirements affecting syndication.

Len said that Donna Harvey, Executive Director of the Department on Aging, wants to assign a staff person to look at housing issues, especially multi-generational housing. Geoff said that he would like an update on Aging and Disability Resource Centers from the Department. Dawn said that Joe Sample, who had been working on ADRCs, had moved to a policy position within IDA.

## **XI. Taskforce Member Reports**

Geoff asked members what issues should be taken up at the November meeting. There was interest in having someone from the Iowa Department of Public Health talk about the Certificate of Need process. Members also suggested that the November meeting was a good time to address legislative priorities.

Ashlea Lantz apologized for not yet having an Employment Committee report. A committee meeting has been set up to discuss the Taskforce position paper. The Association of Persons Supporting Employment for People with Disabilities (APSE) is holding its conference on September 24-25.

Roxanne Cogil mentioned the D.D. Council's Self Advocacy Conference held the previous week. She also mentioned that a high school senior in Johnston is in the running for Homecoming King.

Michele expressed great pleasure at the ability to participate in the IFA housing conference, and in meeting Nadine Green, who presented on non-discrimination requirements for rental properties. Ms. Green has co-authored a pre-teen book entitled *Libby and the Cape of Visitability*, written from a child's perspective, on the pain caused by feelings of exclusion.

Geoff will be testifying before the Senate Health, Education, Labor and Pensions Committee in its last disability-focused hearing.

## **XII. Public Comments**

Dawn provided an update on Senator Harkin's roundtable on July 25<sup>th</sup>, to discuss the ADA. Michele Meadors was a member of the panel, and received many compliments. At the reception Michele gave Senator Harkin the award from the Iowa Disability and Aging Advocacy Network (to which the Taskforce had signed on). The award will hang in the front hall of the Harkin Institute. Michele believes the event brought new awareness of disability issues to the Institute.

## **XIII. Adjournment**