

MENTAL HEALTH AND DISABILITY SERVICES COMMISSION
June 16, 9:30 am to 3:00 pm
Center for Disabilities and Development, Rembolt Room 115
100 Hawkins Drive, Iowa City, Iowa
MEETING MINUTES

MHDS COMMISSION MEMBERS PRESENT:

Neil Broderick	Cindy Kaestner (by phone)
Lynn Crannell	Linda Langston
Lynn Grobe	Gary Lippe
Representative Dave Heaton	Zvia McCormick
Jan Heikes (by phone)	Laurel Phipps
Richard Heitmann	Dale Todd
Chris Hoffman (by phone)	Jack Willey
David Hudson	Craig Wood

MHDS COMMISSION MEMBERS ABSENT:

Senator Merlin Bartz	Representative Lisa Heddens
Richard Crouch	Susan Koch-Seehase
Senator Jack Hatch	Gano Whetstone

OTHER ATTENDEES:

Tammie Amsbaugh	U of Iowa, CDD and Iowa MHDS, IME
Theresa Armstrong (by phone)	DHS, MHDS, Community Services & Planning
Kris Artley (by phone)	Johnson County CPC Administrator
Bob Bacon	U of Iowa, Center for Disabilities & Development
Jennifer Britton	U of Iowa, CDD (COMPASS)
Connie Fanselow	DHS, MHDS, Community Services & Planning/CDD
Meredith Field	U of Iowa, Center for Disabilities and Development
Jennifer Harbison (by phone)	DHS Legislative Liaison
Linda Hinton (by phone)	Iowa State Association of Counties (ISAC)
Lenore Holte, PhD	U of Iowa, CDD
Julie Jetter	DHS, MHDS, Community Services & Planning
Gretchen Kraemer (by phone)	Iowa Attorney General's Office
Karalyn Kuhns (by phone)	DHS, MHDS Interim Administrator
Brooke Lovelace	U of Iowa, CDD and DHS Iowa Medicaid Enterprise
Vickie Miene	U of Iowa, CDD and Community Circle of Care
Royann Mraz, MD	U of Iowa, CDD and IU Health Care
Liz O'Hara	U of Iowa, Center for Disabilities and Development
Chuck Palmer (by phone)	DHS Director
Jim Pender	ISU/DHS Targeted Case Management
Mary Peterson (by phone)	DHS, Mental Health and Disability Services

OTHER ATTENDEES (continued):

Ann Riley	U of Iowa, Center for Disabilities and Development
Joel Ringdahl, PhD	U of Iowa, Center for Disabilities and Development
Joe Sample	Iowa Department on Aging
John Severtson	Opportunity Village, Clear Lake
Elayne Sexsmith	U of Iowa, Center for Disabilities and Development
Jan Shaw (by phone)	Johnson County MH/DS Services
Deb Westvold	ISU/DHS Targeted Case Management
Dion Williams	Systems Unlimited/Johnson County MH/DS Planning Council

WELCOME AND CALL TO ORDER

Chair Jack Willey called the meeting to order at 9:35 am. Jack welcomed Commission members and guests and led introductions. Quorum was established. No conflict of interest issues were identified for this meeting. Jack welcomed new Commission member Lynn Grobe to his first meeting.

APPROVAL OF MINUTES

Lynn Crannell made a motion to approve the minutes of the May 18 and May 19, 2011 meetings as presented. Craig Wood seconded the motion. The motion passed unanimously. Jan Heikes, Chris Hoffman, and Cindy Kaestner were present by phone for the vote.

MHDS DIVISION UPDATE

Theresa Armstrong shared an update on disaster mental health activities. The DBHRT (Disaster Behavioral Health Response Teams) were called out to assist with the flooding situation on the Missouri River. The DBHRT teams are trained volunteers, many from provider agencies and community mental health centers. They were called on by the Governor's Office to go door to door and talk about evacuation planning to local residents, as well as working with emergency outreach centers to get information out to individuals living in at-risk areas. They targeted about 3000 homes in the Council Bluffs area. The Iowa concern hotline is being used as a resource. They are receiving calls and making referrals for DBHRT assessment when they feel it is appropriate.

UPDATE FROM DHS DIRECTOR CHUCK PALMER

DHS Director Chuck Palmer indicated that since Representative Heaton was present he would defer to him to update the Commission on the status of mental health redesign legislation. DHS Legislative Liaison Jennifer Harbison will be joining the call later to offer her perspective as well.

As Theresa Armstrong noted, a major focus of DHS over the last few weeks has been the flooding in western parts of Iowa. Good work has been going on at Glenwood Resource Center to help address some of the needs of that area of the State. They opened up their campus to alternative settings at risk of being flooded out and have been serving as a staging area for services to that part of the State. DBHRT teams have also been very active. The concern is that the magnitude of the flood is much more than many of the levies in that area have previously been subjected to, with as many as 30,000 individuals potentially affected. The DBHRT team members have been going door to door and finding out how many folks are feeling stressed and need information to increase their awareness. A contingency plan has been developed for use in the event that the water treatment plant is affected.

Representative Dave Heaton outlined progress on mental health redesign efforts in the legislature. He explained that one of the main points of contention between the House and the Senate is funding for mental health. The House added another \$20 million to address the mental health and disability needs managed by the counties; the Senate feels strongly that the \$20 million included in Senate File 209 was adequate. The House has since reduced that amount to \$17 million in the latest proposal. There would then be a total of \$37 million, with \$10 million on that going directly to counties with current waiting lists, \$5 million of it going to reduce the Waiver waiting lists, and the rest going into the Risk Pool Fund to be distributed to counties from there. He said the additional money that the House proposed is being redirected to preschools and the Regents and the House and Senate are at an impasse on that issue.

Chuck Palmer noted that legislators have gotten a clear message that with the loss the ARRA (American Recovery and Reinvestment Act) federal stimulus dollars counties are underfunded.

Representative Heaton said that in the area of children's mental health, the House is proposing a \$250,000 appropriation for the Central Iowa Systems of Care project and the Senate is proposing \$257,000. The House is also proposing another \$160,000 to fund a new system of care project in the Cedar Rapids-Mason City Area. The budget also proposes money to increase the level of state participation for the Community Circle of Care project in the Dubuque area as the SAMHSA (Substance Abuse and Mental Health Services Administration) federal grant funding is being phased out. The House proposal includes a revolving loan fund that would provide 1% loans to buy down the cost of capital for the establishment of Waiver homes for people with high behavioral needs, Waiver homes for people with autism, and for in-state facilities to serve people who are currently being served out of the state. The Senate is in agreement with that provision.

The language for mental health redesign is now in the Omnibus Bill. Representative Heaton said House and Senate members have not yet had a meeting to work out their differences. The House does not see a need to make the changes proposed in Senator Hatch's 19-point amendment.

Jack Willey asked Representative Heaton what the Commission could do to contribute to the process. Representative Heaton said he does not believe that \$20 million is adequate to address the need for counties. Since the one-time money is now gone, a smooth transition must be built from where we are to where we are going and the mental health needs of our communities must be addressed. He said he appreciates the Governor's Office and House leadership supporting the investment of additional dollars and thinks the Senate should hear that message from the Commission and other advocates.

Jennifer Harbison added that the legislation has not yet been finalized, but DHS is moving forward with planning and receiving names for the various workgroups that are proposed under the Omnibus Bill language that came from Senate File 525 and remaining positive that the legislation for mental health redesign will be passed.

Director Palmer said that over the next month or so the Department will be working with the Commission and other groups to get good representation for the workgroups. Groups will most likely be looking at core services and funding approaches for mental health and intellectual disabilities, at the implications of the State taking on more responsibility for brain injury services, at the role and function of a regional structure, and at juvenile services, which involves the relationship and interface of mental health, juvenile justice, education, and child welfare. There are also issues around commitment and the area of workforce and scope of practice that will be addressed by the workgroups. They will have a very full agenda and a lot of work to complete in a short period of time from mid to late July until about the end of October. DHS is currently gathering names and trying to figure out how to be inclusive, have a broad representation of people, including consumers, and yet keep the groups small enough to get their work done efficiently because they have significant products to develop.

Laurel Phipps asked if cuts will be made proportionally. Director Palmer responded that there is not an across the board budget cut in effect. The Governor is working to address a level of funding for entitlement programs to operate without supplemental funds. Supplemental funding has been used to continue to support the number of beds that existed lasted January in the State institutions. There will be some layoffs, and some staff vacancies have been held open, although that can depend on where the vacancies occur. To maintain health and safety, the Department is trying to keep child abuse and social work staff as close as possible to the level it was at on January 1, 2011. They are continuing to work from priorities. Programs that are shown to be less effective or areas where technology can change the way business is done may require rethinking or redesign. Health care reform may also bring changes and that is likely to be continued movement in the service mix.

Craig Wood asked what would happen if the Omnibus budget bill does not pass – if redesign would be put on hold for another year, or if there would possibly be another bill. Representative Heaton responded that if that were to happen, the legislature could act to move the sunset date on the old system and continue to work. He added that he is anxious to get started and does not want to do that. He said if some agreement on

dollars can be reached between the House and the Senate, he believes the differences on the policy part of the bill can be hammered out. The difference in the amounts of funding is the key concern.

Jack Willey asked if progress has been made in the search for a new MHDS administrator. Director Palmer responded that the Department has received applications from a number of candidates from both in-State and out-of-State and they include some very qualified individuals. Work is currently being done to sort out the applications and determine their level of interest. Interviewing is likely to start after the first or second week of July and September 1 might be a realistic date for a new hire.

EMERGENCY EFFORTS AT GLENWOOD STATE RESOURCE CENTER

Zvia McCormick shared information on activities to assist in the Missouri River flooding emergency that have been undertaken at Glenwood State Resource Center. A 50-bed emergency center has been set up and is ready for use if it is needed for the Mills County area. There is also a larger emergency center set up at the high school. The Department of Transportation has evacuated much of its equipment to the Glenwood campus.

The Department of Natural Resources has partnered with Americorp and they have provided 16 to 18 individuals to help with flood-related efforts. They are being housed at GRC. The residents of Pacific Place, a 12-bed ICF/MR in Pacific Junction that was clearly going to be flooded have already been evacuated to Glenwood, which had an ICF-qualified building available for their use. They have also been in discussions with a large PMIC in Council Bluffs that serves about 45 children. They are also working with the Red Cross and looking for something closer to home, but may bring some of the children to Glenwood if other options are not found. Other families may choose to bring their children back home if they do not live in the flood area. If some of the children are moved to Glenwood, they would continue to be served by the PMIC staff.

GRC is providing housing for some staff members who have been affected by the flooding, and for their pets, which is very important to them. If the city water system is breached, Glenwood has its own system that would supply them for about 2 weeks. They have also purchased a two month supply of drinking water and have their own generators. It is not anticipated that the city system will be shut down, but if so, GRC would be better situated than the rest of the town. The GRC staff is trying to do everything they can for the community without overtaxing themselves and their resources.

Karalyn Kuhns noted that DHS Targeted Case Management (TCM), which is also part of the MHDS Division, has contacted their consumers to make sure they are safe and see that they get moved if necessary. They are also working with local offices that might be in an affected area. IME (Iowa Medicaid Enterprise) held a statewide call for all TCM agencies very early on to touch base with people and make sure they were proactive in planning and keeping safe.

RECENT COURT RULING ON PRIVACY OF MEDICAL RECORDS

Gretchen Kraemer shared information on a new court ruling of interest with regard to the confidentiality of mental health records. *Mulligan v. Mulligan* is a decision in a dissolution case issued by the Iowa Court of Appeals yesterday. It is a companion case to *Ashenfelter v. Mulligan*. It strengthens the protections around medical and mental health records, even in the context of a legal dispute. It holds that there is a constitutional right to privacy, although it is qualified and there are times it can be over-ridden.

In the criminal context, the court has balanced the right to a fair trial against the individual's right to privacy in their health records. This case is interesting because it is a dissolution case and there are child custody issues. The husband had requested extensive mental health and medical records for the wife, including any commitment records, hospital records, treatment records, and testimony from doctors and treatment providers. The court said that this was not a case where the litigant had not put her mental health at issue (for example, claiming emotional damages), so the litigant exception did not apply. It decided that because this was a civil matter and did not involve the countervailing constitutional right to a fair trial, that there is not countervailing interest that would outweigh the wife's privacy rights.

This is an important ruling for people who are involved in this type of litigation. The only civil case the decision seems to leave open is for the ability of a court to order disclosure of medical or mental health records to the State in a CINA (Child in Need of Assistance) action. So there is still an avenue when there is a protective concern related to children. There is also still an opportunity for the court to order an independent evaluation in a dissolution case, which is probably a more appropriate avenue because it would be targeted to the questions that are at issue as opposed to allowing litigants to search through year of personal information "fishing" for something to leverage against the other party.

Gretchen said she also wanted to remind anyone who might be receiving a subpoena that a subpoena is not a court order and it is advisable to get your counsel involved and often to file a motion to quash to get the court to take a look at what is being requested so that people's privacy rights are being protected.

Dale Todd asked Gretchen if she had any updates on cases filed by people on waiting lists for waiver services or if there were any trends emerging. Gretchen responded that the Department of Justice has been very active in filing actions over the last year. She noted that the Georgia case has been settled and touted as a victory by both sides, which should indicate a successful settlement.

A ruling was issued last week in the Arkansas case at the Conway Developmental Center and the Department of Justice lost. The case dealt with CRIPA (Civil Rights of Institutionalized Persons Act of 1980) and ADA (Americans with Disability Act) provisions and the court issued a lengthy and detailed 85-page opinion, saying that the

Department made some very serious and concerning allegations, but had not been able to support them with evidence.

JOHNSON COUNTY MANAGEMENT PLAN CHANGES

Julie Jetter shared an outline of proposed changes to the Johnson County Management Plan. Johnson County CPC Administrator Kris Artley and Jan Shaw from Johnson County MH/DD Services were on the phone to answer questions. Julie indicated the proposed changes have been taken to a public hearing and the Johnson County Board of Supervisors has approved them. Since the changes include some that are more restrictive, the Commission also needs to vote on a recommendation to the Director for approval.

The first adverse change is “changing income eligibility for all county founded services from 200% to 150% of FPL” (federal poverty level). 150% FPL is the floor under State rules and the majority of counties already use 150% FPL as the income standard for eligibility. Zvia McCormick asked how many individuals would be affected by the 200% to 150% reduction. Kris Artley responded that the county did a survey in January and expects that about 100 of the people receiving services at that time would be affected.

The second adverse change is “Medical staff can request an exception to policy when a potentially life threatening emergency exists not when the individuals just exceeds the authorized service units.” In response to a question from Gary Lippe, Kris Artley responded that in the past the county had allowed CMHCs to ask for exceptions to the number of units allowed and that request might come from a clerical person simply because the client was running out of units. With this language, a request from more units would have to come from the physician so it would be based on clinical need, not billing units. Craig Wood asked how many service units are authorized under the Johnson County Plan. Kris Artley responded that initially there are 16 psych unit and 24 therapy units available per year for a client.

The third adverse change is “Added clarification on repayment policy when someone received excessive resources – failure to make repayment may result in ineligibility for the time period in which the resources could have covered services and that the individual has 60 days from receipt of excessive resources to meet resource limited of \$2000.” The previous language was very open ended. This new language identifies a set time frame. David Hudson asked if the time frame is typical. Julie responded that 60 days is typical.

Dale Todd asked if Johnson County was levying the maximum amount. Kris Artley responded that they are levying 100% and have been for a number of years. They are looking at being \$2.25 to \$2.5 million short in meeting their budget for the fiscal year that starts July 1 with no increase in allowable growth.

Gary Lippe asked what kind of impact eliminating 100 people from eligibility would have on the county budget. Kris responded that it would be nominal in terms of a \$2.5 million

shortfall and they will have to come back with another plan, cutting services from the matrix if there is not additional money forthcoming.

Jan Heikes asked if they had considered a sliding fee scale. Kris responded that they had tried it in the past and found it was not workable. Cindy Kaestner noted that CMHCs end up carrying a lot of bad debt for fees that are simply uncollectible.

Linda Hinton commented the counties are in a difficult position and are looking first at cutting things they do not have to fund; they do not have to fund people with income over 150% of FPL. Kris Artley said that change is estimated to save about \$320,000. Johnson County does not have a single program for component that can be cut to save enough money for the anticipated shortfall, so they will have to cut what dollars they can from every single component of the program. Dion Williams added that they are trying to cut "a little here and a little there" to get to \$2.4 million, and they are trying to do so in a way that minimizes the damage to individuals.

Lynn Crannell made a motion to recommend that the Director accept the proposed revisions to the Johnson County Plan. Linda Langston seconded the motion. Discussion: Chris Hoffman said this is the second time in recent memory that this kind of cut has come to the Commission and he wants the record to reflect that the Commission and the county are doing what they have to do in this situation, but cutting services is not what they want to be doing. Linda Hinton added that there continues to be a call for consistency in services statewide, but we are seeing that translate into more counties reducing their services to the median level.

Kris Artley said that the vast majority of services cannot be cut and the county has to look at what can be cut. The Johnson County MH/DS Planning Council was in agreement that this was one of the less damaging ways to make cuts that had to be made and the Board of Supervisors accepted their recommendation. Linda Langston commented that Linn and other counties have had to make similar decisions and they are always difficult.

Representative Heaton asked whether Johnson County would go back to funding people up to 200% of FPL if the legislature addresses the shortfall. Kris Artley responded that she expects the eligibility will stay at 150% because the county has had about 19% population growth since the last census, and looking ahead to regionalization, that would be consistent with other area counties. Dion Williams added that in making the cuts, the MH/DS Planning Council also discussed and prioritized how they would restore them if additional funds became available.

A vote on the motion was called. Thirteen of the members present voted in favor. Dale Todd and Gary Lippe voted against. The motion carried 13 to 2.

WELCOME AND OVERVIEW OF CDD

Administrator Elayne Sexsmith welcomed Commission members and guests to CDD, saying she was pleased to have the opportunity to talk about the programs offered by the Center for Disabilities and Development and how they serve as a resource for Iowans. She presented an overview of CDD's history, current initiatives, and plans for the future.

CDD's mission is to "Improve the health and independence of people with disabilities and advance the community systems on which they rely." Its identity as Iowa's University Center for Excellence in Development Disabilities (UCEDD) takes CDD beyond health care. CDD celebrated its 60th anniversary in 2008. The clinical program is principally pediatric, but also serves some adults – about 20%.

CDD staff also work on policy, systems change, research, and training the next generation of health care providers, and have pulled together unique resources to move those efforts forward. Including faculty, staff, and student volunteers, they are 200 strong. The areas of CDD's mission are inter-dependent.

The clinical program historically provided care to individuals with developmental disabilities (DD). The core of the patient population are individuals with physical disabilities, but there are now also many referrals for challenging behavior, autism, ADHD (Attention Deficit Hyperactivity Disorder), and learning disabilities, as well as many children who have complex issues. CDD has been quietly growing over time and is on track for more than 8100 outpatient visits for fiscal year 2011, which translates into more than 32,000 patient contacts.

Elayne shared a map showing patient contacts by county. It is common for families to travel from across the state looking for recommendations they can take back to their homes and schools. Many families come to CDD for occupational therapy (OT), physical therapy (PT), speech therapy, and now behavioral therapy is also being offered. Referrals come from many different sources, including physicians, hospitals, schools, and other families. CDD coordinated with physicians in the main children's hospital and it is expected that CDD will actually move in the next five years to be located within the hospital.

CDD continues to have a growing number of new patient referrals – 2800 for fiscal year 2011. Over 70% of the patients seen are Medicaid qualified, and others are supported from multiple sources of payment. The map shows a lot of contacts in the Des Moines area and much of those contacts have statewide implications.

IOWA'S UNIVERSITY CENTER FOR EXCELLENCE

Bob Bacon, CDD Director of Disability Policy and Training welcomed everyone, saying he appreciates the opportunity for members of the Commission and other guests to learn more about CDD. He noted that CDD has been a partner with DHS in many areas

over the last decade. Bob explained that he directs the University Center for Excellence component of CDD. The program started in 1952 as a long term residential school for kids with disabilities. It has evolved over time as the expectations of society and people with disabilities have changed. There was not a place for children with disabilities to go to school in Iowa in the 1950s and 60s. When the IDEA (Individuals with Disabilities Education Act) was passed in the 1970s, kids had the right to attend schools in their neighborhoods and communities.

When kids came here to the “hospital school,” they stayed for 180 days. In 1963 federal legislation known as the DD (Developmental Disabilities) Act was passed that created University Affiliated Facilities. UAFs later became UCEDDs (University Centers for Excellence in Developmental Disabilities). Being Iowa’s UCED extends CDD’s mission to more than a clinical program. A UCED is expected to serve core functions, which include:

- pre-service training
- community education
- technical assistance
- research
- information dissemination

There is at least one UCEDD in each state; CDD is the only one for Iowa. It operates on many grants and contracts. The UCEDD grant is about \$535,000; it is an “administrative seed grant” used to buy in to key faculty and staff members who can leverage other external funding sources to advance the productivity and inclusion of people with disabilities. It is unique because usually it is impermissible to use grant resources to leverage other grant resources, but that is actually the purpose of the UCEDD grant.

This structure is what enables CDD to be a close partner with DHS and other state agencies. DHS and CDD have collaborated on:

- Conner training Consortium (1987 and ongoing)
- Medicaid Infrastructure Grant (MIG), the Medicaid buy-in program (1999 to present)
- Iowa’s first Real Choices Systems Change Grant (2002-2005)
- Robert Wood Johnson Cash and Counseling Grant (2004-2007), which led to the Consumer Choice Option for HCBS Waivers
- Real Choices Systems Transformation Grant (2005-2010)
- Money Follows the Person (2008-2016)
- SAMHSA Community Circle of Care (2006-2012)
- Family Support 360 (2010-2012)
- Technical Assistance to the MHDS Division (2009-2012)

For more information about CDD’s UCEDD-related programs, visit: <http://www.healthcare.uiowa.edu/edd/ucedd.asp> or <http://www.aucd.org>

The UCED concept grew out of President's Committee on Intellectual Disabilities Report of 1963 that recognized if the country was going to move away from institutional model of care for people with ID, there would need to be community capacity built. UCEDs have been able to show that we are a good investment because for every UCED federal grant dollar invested, they are able to leverage significant other resources.

David Hudson asked if CDD has an adaptive equipment program. Bob responded that they have UERS (Used Equipment Referral Service), which serves as a clearing house for adaptive equipment. Bob was also asked if CDD provides legal assistance. He responded that they do not do so directly, but Iowa Compass connects people with resources they are seeking, including legal. CDD has been the home for IPAT (Iowa Program for Assistive Technology), Iowa's Tech Act project since 1989.

Bob referred people to the MHDS State Olmstead Plan document, "History of Disability in Iowa" for more detailed information on how things have evolved in the State.

IOWA'S LEND PRE-SERVICE TRAINING PROGRAM

Bob Bacon introduced Dr. Lenore Holte, Professor in the Department of Communication Sciences and Disorders as well as the Department of Pediatrics in the College of Medicine. She is responsible for the Audiology Department at CDD and also directs the LEND (Leadership Education in Neurodevelopmental and related Disabilities) project, which is the core of CDD's pre-service training initiative.

One of CDD's core missions is to provide pre-service training to professionals who are going to serve people with developmental disabilities. CDD has many pre-service training activities, with the LEND program being the biggest component.

During the last academic year, about 250 trainees came through the clinical programs. Most were graduate students at the University of Iowa, but they also include post-doctoral fellows, residents, and students drawn from other universities. Of those, 139 were short-term trainees (less than 40 hours), 53 were intermediate term trainees (40 to 300 hours), and 63 were long term trainees, putting in more than 300 hours. Most of the trainees participated in training in an interdisciplinary clinical environment, and a select group of the long term trainees are funded by the LEND program, which combines clinical, leadership, and advocacy training. The goal is to train the next generation of leaders in service provision for people with developmental disabilities. Students come from a variety of disciplines, including pediatrics, psychology, audiology, health administration, speech, nutrition, dentistry, social work, nursing, and other fields.

The LEND program is federally funded by the Maternal and Child Health Bureau (MCHB), a part of the Health Resources and Services Administration (HRSA). The Iowa LEND program receives about \$500 to \$600 thousand dollars each year, which is used for trainee stipends, faculty and staff salaries, equipment and supplies, and travel for trainees and staff.

The training goals are set by MCHB:

- To assure a workforce that possesses the knowledge, skills, and attitudes to meet unique maternal and child health needs.
- To prepare a diverse workforce that is culturally competent and family-centered.
- To improve practice through interdisciplinary training.
- To develop effective maternal and child health leaders.

There is currently a national network of thirty-nine LEND training programs. The goals are:

- Family centered care
- Cultural competence
- Interdisciplinary clinical work
- Disability information
- Community healthcare services
- Advocacy and policy
- Leadership
- System improvement

Trainees participate in a wide variety of interdisciplinary clinical work and work closely with staff members in the Healy Clinic. Each completes a minimum of 150 clinical hours, and most put in far more hours.

The Parents as Mentors (PAM) program pairs trainees with a family that has a child with a disability and the student participates in daily activities with the family, which provides really valuable insights about the needs and experiences of families. They also participate in cultural competence activities on campus and in the community.

Trainees come together for Tuesday and Thursday noon seminars to share “cases” they see, learn from each other, and get an interdisciplinary perspective. This sharing is one of the strengths of the program and helps create a cohesive group of trainees.

One of the areas of emphasis in recent years is Autism and Autism Spectrum Disorders (ASD). Congress passed the Combating Autism Act in 2006, which provided additional funding to LEND programs to expand training in treatment of diagnosis of children with Autism related disorders and help students to learn how to evaluate diagnostic instruments and therapy techniques to determine best practices. CDD was able to use supplemental funding to bring in more trainees in psychology and speech language pathology, and to provide ADOS (Autism Diagnostic Observation Schedule) training, which is considered the “gold standard” diagnostic technique for Autism Spectrum Disorders.

To get an appreciation for the challenges of families who access services and care in a rural setting, LEND trainees go out into the community to learn about and work with community-based health providers, including:

- Federally Qualified Health Centers (FQHC)
- Pediatric Dentistry Clinics (including the WIC (Women, Infants, and Children) program)
- Community Health Centers
- Child Health Specialty Clinics

Annually LEND staff and trainees from Iowa, South Dakota, Nebraska, Missouri, Kansas, and Minnesota, which form the Midwest LEND Consortium, hold a meeting to connect and share ideas and information. Iowa LEND trainees also engage in advocacy and policy and most recently traveled to Washington, D.C. where they attended the National Disability Policy Seminar and Senator Harkin's Constituent Breakfast.

They have engaged in a long list of activities and projects, including for example:

- Hearing screening for the children of migrant farm workers
- Special Olympics National Nutrition Survey
- Poster and oral presentations at national conferences
- Telehealth research project for behavioral assessments
- Process improvement for the Healy Clinic Schedule
- Autism training modules
- Distance learning seminars
- REACH (Realizing Educational and Career Hopes)

Many former Iowa LEND trainees are now employed at CDD, at other universities, hospitals, medical centers, and other facilities, including Boys Town.

OLMSTEAD PLANNING AND TECHNICAL ASSISTANCE

Bob Bacon talked about Olmstead planning, which is one of the areas where CDD has been providing technical assistance to DHS through a variety of resources. He said the legislature has wisely acknowledged that Olmstead principles must be at the forefront of redesigning Iowa's services system.

Olmstead said it is discrimination under the ADA (Americans with Disabilities Act) if a state administers its service system and programs in such a way that individuals do not have a real choice about living in the community. Olmstead is not just about where you live, but also about how you spend your day. The Supreme Court ruling was made in 1999. There was a very important "Dear State Medicaid Director" letter that was issued in 2000, which said states need to have "effectively working Olmstead Plans." Implementation efforts were undertaken in Iowa. The Olmstead Consumer Task Force was involved in that a decade ago. Executive Order 27 was signed by Governor Vilsack in 2003 and efforts have continued.

The Obama Administration stepped up the pace of enforcement. Another major Olmstead settlement was announced in Illinois just yesterday. The U.S. Department of Justice is now active in 35 states with settlement agreements, findings letters, or responding to individual complaints from consumers. Taking note of what has been happening in so many states, in 2009 Iowa decided to update its “effectively working” Olmstead Plan. The five goals of the current Plan include:

- Welcoming communities
- Increased access to information services and supports
- Community capacity building
- High quality services and supports
- Accountability for results

At the federal level the Dept. of Justice has been the “stick,” but other federal departments have offered “carrots” and one of the roles CDD has played is to help Iowa take advantage of those opportunities, including Money Follows the Person, employment-related initiatives, and workforce training initiatives. All of those projects can be linked directly to Iowa’s Olmstead Plan and reflect a partnership between DHS and CDD. CDD and DHS worked together to write the Money Follows the Person Grant, the Real Choices Systems Transformation Grant. Because CDD is a UCED, it has resources that can be committed to those kinds of collaborative efforts.

Iowa having an effectively working Olmstead Plan assists DHS and other Iowa stakeholders in taking advantage of and knitting together federal initiatives in a way that helps finance needed systems change. The Olmstead Plan has also made it easier for stakeholders to recognize and create needed state partnerships. Olmstead is a non-partisan issue. President Bush issued an executive order at the federal level calling on agencies to identify barriers to community living. Executive Order 27 did the same thing here in Iowa. It takes the coordination of all agencies to implement Olmstead. Many of the initiatives in the Olmstead Plan include those which come from other agencies or are shared with other agencies. Bob concluded by saying, “you can always count on CDD to contribute to efforts to make life in the community possible – it’s what we do.”

IOWA’S MONEY FOLLOWS THE PERSON GRANT

Brooke Lovelace shared a handout with updated statistics on the Money Follows the Person (MFP) Grant. MFP has been reauthorized through 2016 with funds available for use through 2019. In addition to helping people move from facility to community settings, it also serves as a needs assessment to help states find out what is needed to support people effectively in the community.

The MFP project has been up and running since September 2008. Since then, 135 people have transitioned out of the ICF/MR (Intermediate Care Facility for Persons with Mental Retardation). There have been two main challenges which are also barriers to life in the community: (1) supporting people with challenging behaviors or aggressions, and (2) providing viable employment supports. A lot of people who are living in facilities are

there because they have had challenging behaviors, aggressions, criminal, or court involvement. Community providers are not equipped to handle those challenges. Since the project started, 15 people have returned to the facility.

Stacy Lane, who has been an MFP transition specialist since the beginning, came with a lot of experience in dealing with challenging behaviors and is a CCI (Certified Crisis Instructor). She has provided consultations with providers and has also carried a full case load. She is now going to become a full time behavior support for providers and a new transition specialist has been hired to carry her case load. She will also work closely with IPART (Iowa Program Assistance Response Team), assisting them with consultations and doing some of their observations and data collection starting this month. The position will be 100% federally funded.

It is also a struggle to find employment options for people as they transition into the community and they often end up relying heavily on pre-vocational and day vocational programs, even though they can work and really need to be working. The result is that they are on such a limited income they cannot participate in their community as fully as they would like. Employment or lack of it affects their lives in many ways. There are no MFP participants that are currently competitively employed. There are plans to hire a full time employment specialist this summer to help address that problem at both an individual and systemic level.

In some cases there are no supported employment providers available in the area and in other cases it may not be possible to find one who is able to serve individuals with a history of aggression or challenging behaviors. The employment specialist will work with local vocational rehabilitation agencies and others doing hands-on job development for people and work with the Iowa State Employment Leadership Network (SELN). They will be able to do some employment activities even before the individual moves out into the community. Brooke noted that there are several individuals ready to move, with a plan to move, and a residential provider lined up, but are waiting until what they are going to do during the day can be identified. The employment specialist will be able work with them. That position will be 100% federally funded also.

Bob noted that CDD actually has more staff members who work around the State than work at the CDD location. The "field" staff include Tammie Amsbaugh, Sarah Renner, and Connie Fanselow who work with the MHDS Division in Des Moines; Brooke Lovelace, who works at the Iowa Medicaid Enterprise in Des Moines; the six MFP transition specialists, Behavioral Specialist, and soon-to-be hired Employment Specialist who each work out of their homes, and the Community Circle of Care staff based in Dubuque.

IOWA EMPLOYMENT INITIATIVES

Tammie Amsbaugh presented information on CDD employment initiatives. Some of the efforts already discussed, such as Olmstead planning and MFP come together under the Iowa Medicaid Infrastructure Grant (MIG). Iowa has been receiving federal funds

through the MIG grant since 2001; it ends December 31st of this year, with a no-cost extension for 2012. CDD has been contracted to provide technical support for MIG since the beginning.

The purpose of the MIG grant is to increase the infrastructure within Medicaid to support employment for Medicaid members. It was used to implement Medicaid for Employed Persons (MEPD) and other initiatives. Currently activities include:

- Supporting Social Security work incentive planning and assistance
- Supporting community-based provider pilot projects trying to re-focus their efforts from facility-based to community-based employment
- Holding work incentive, employment, and self-employment seminars
- Distributing work incentive calendars

“Success story” videos are available to share stories of success by people with disabilities in designing and operating businesses.

MIG strategically involved the State of Iowa in the State Employment Leadership Network, which is a collaborative effort between the University Center for Excellence in Disabilities (UCED) from Massachusetts, the Institute for Community Inclusion, and the NASDDDS (National Association of State Directors of Developmental Disability Services) to provide assistance to states in improving employment outcomes. About 20 states are members of the network.

They have helped us identify the issues that need attention in Iowa and focus our efforts, including building community provider capacity and reviewing provider funding and reimbursement rate. Right now, there is a financial incentive to provide facility based employment services over community based. They are helping us look at what is going on in other states to address similar issues.

Tammie shared a matrix of the employment efforts in Iowa, including:

- The Alliance for Full Participation
- Employment First
- State Employment Leadership Network
- Governance Group

They all share conceptual goals:

- Aligning policies and funding
- Creating strong partnerships
- Showing data driven outcomes
- Utilizing best practice transition services
- Working with businesses to influence other businesses
- Sharing information at the grassroots level
- Utilizing innovation, training, and technical assistance

Tammie explained that she works with the State Employment Leadership Network, which ties into Strategic Priority #5 of the Olmstead Plan: “Establish the leadership, necessary partnerships, and infrastructure for a service system expanding opportunities for competitive employment.”

The Olmstead team has agreed on an employment vision: “Employment in the general workforce is the first priority and the expected and preferred outcome in the provision of publically funded services for all lowans with disabilities.” That is consistent with the Employment First vision nationally. It is also important to define what we mean by “employment.” Employment is defined as: “regular or customized employment in the general workforce, where employees with disabilities are paid by the business (unless self-employed) earning at least minimum or prevailing wages and benefits.” That includes having ordinary opportunities for meaningful interactions with co-workers without disabilities, customers and/or the general public.

One of the main concerns is aligning policies with the funding structure, rates, and methodologies. Right now in Iowa, we are spending about 80% of our employment-related service dollars on facility based activities and we need to change that to align our policies with our goals. The U.S. Department of Justice recent cited the State of Virginia for over-reliance on facility-based programs and sheltered workshops.

Employment impacts Medicaid claims, and other costs and it’s about being part of the community – it is the right thing to do both socially and economically.

Representative Heaton spoke about a manufacturing facility in north western Iowa that employs people with disabilities and people without disabilities working side by side in a blended model, earning good pay and benefits. He said it works well and makes money, and more businesses should be looking at using a similar model. He noted that there may be some resistance to people with disabilities taking jobs when there is a shortage of jobs available. Tammie commented that people with disabilities are impacted by the economic downturn much the same as people without, but since many of them were unemployed or underemployed in better times, they start out at a lower economic level.

Tammie noted that it is important to get the word out about employment success stories like the one Representative Heaton shared and show employers who can be models for others.

A lunch break was taken at 12:35 p.m.

The meeting reconvened at 1:15 p.m.

IOWA DIRECT CARE WORKFORCE INITIATIVE

Ann Riley presented information on the Direct Care Workforce Initiative. She said workforce development has been in issue in building capacity for years. Since 2004 the

Iowa Department of Public Health has been working on the Direct Care Workforce Initiative. At that time it started out as a legislatively created task force to work on building the capacity of health and long term care workers. They wanted a consistent curriculum, to reduce the need for re-training when people move from setting to setting, and build the quality of the workforce by providing career opportunities.

They also recognized that as people with disabilities move into the community, they need a lot of the same types of services as the aging population, but there are differences. The group came to include members who work with disability populations as well. In 2006 the Iowa General Assembly made the task force into a council and directed them to develop a credentialing system.

By 2030, 25% of Iowa's population is expected to be over age 65 and in need of long term care services. People with developmental disabilities may also be in need of additional services as they age. Research indicates that Iowa currently has a baseline of about 50,000 direct care workers who use titles tracked by Iowa Workforce Development. That does not include many people who work with persons with disabilities to provide respite, supported community living, supported employment, and other similar services. The Iowa Association of Community Providers estimates that there may be as many as 50,000 other workers not counted in that baseline. Even then, it is anticipated that by 2018, Iowa will need a minimum of 11,000 more workers.

Ann shared a handout showing an overview of the curriculum that is now being piloted and will be mandatory when it goes into effect in three years.

All workers will start with a 5 to 6 hours introductory core curriculum with an option to take additional modules that will accumulate to give them one of three different kinds of credentials. The additional training modules include:

- Home and Community Living
- Instrumental Activities of Daily Living
- Personal Support
- Personal Activities of Daily Living
- Health Monitoring and Maintenance

The three types of professional credentials are:

- Community Living Professional
- Personal Support Professional
- Health Support Professional

Specialty endorsements are also being developed in areas approved by the Iowa Board of Direct Care Professionals, including:

- Autism
- Alzheimer's/Dementia
- Advanced Nurse Aide
- Brain injury
- Mentoring
- Crisis Intervention
- Hospice and Palliative Care
- Medication
- Mental Health

- Paid Nutritional Assistant
- Positive Behavior Supports
- Psychiatric Care
- Wellness and Prevention

The piloting will provide feedback on how effective the curriculum is in getting workers the training they need.

COLLEGE OF DIRECT SUPPORT

Meredith Field presented an overview of another training initiative to build the capacity of the direct care workforce, the College of Direct Support. There has been a pilot project in Iowa since 2009 using the College of Direct Support, which is an online curriculum and learning management system based at the University of Minnesota's UCED (the Institute for Community Integration). They have been developing courses specifically for the direct care workforce for about ten years. There are a variety of different courses focusing on issues including:

- Community inclusion
- Cultural competence
- Civil rights and advocacy
- Direct Support professionalism
- Positive Behavior Supports

For two years now, federal funds from the Real Choices Systems Transformation Grant and Money Follows the Person have paid for access to the training to build the capacity to make it possible for individuals to transition from facilities to community settings using MFP by educating a workforce of direct support professionals to serve them. The training is available to providers and their staff using MFP, families, case managers, social workers, and anyone who touches the lives of people transitioning through MFP. At this point, about 40 providers across the State are involved and have about 1500 workers enrolled in the program. In the two years of the pilot program, workers have completed 10,938 lessons for a total of 9730 training hours.

Nationwide, about 36 states are using the College of Direct Support; 14 states are using it statewide, and 5 states have mandated its use as a result of Department of Justice settlements. There are a series of courses that are directed toward frontline management and supervision to address workforce retention issues. It is estimated that by 2018 the number of direct support workers who are providing home and community based services will out number those working in facilities by two to one.

Meredith showed a brief demonstration of CDS online. Courses include audio stories, video stories, and interactive opportunities. They follow a similar template, all have pre-tests and post-tests and tools that administrators can use to assign training, monitor progress, and pull reports. Data are being gathered to demonstrate to the legislature that the training is increasing competency and reducing the rate of turnover. Meredith explained that turnover is impacted because workers are better prepared to communicate effectively with their clients, deal with challenging behaviors, and plan for or prevent crisis situations. Bob Bacon commented that the CDS is an example of

something that should become a permanent part of the Iowa system because it builds capacity and helps providers access state-of-the-art staff training without cost to them.

EVIDENCED-BASED TREATMENT FOR AUTISTIC SPECTRUM DISORDERS

Dr. Royann Mraz, Clinical Associate Professor of Pediatrics at the University of Iowa Children's Hospital and Medical Director at CDD, presented on Evidenced-based Treatment for Autistic Spectrum Disorders.

Autistic Spectrum Disorders:

- Have a prevalence rate of 1 in 110 children
- They are a group of brain-based neurodevelopmental disorders
- There are three main characterizations:
 - Impaired social interactions
 - Delayed and impaired communication
 - Repetitive and stereotypic behavior and restricted interests
- Onset is usually before age 3
- About 50% have intellectual disabilities
- The ratio of males to females is 3:1 to 5:1
- Only 10 to 15 % of cases have a known cause
- Heavy genetic influence
- And possible environmental factors

Generally Accepted Principles of Early Intervention:

- Start as soon as possible
- Treatment must be individualized
- Intensive educational program for 20 to 25 hours per week
- Low student to teacher ratio
- Family involvement

Early Intervention Strategies:

- Developmentally appropriate educational activities
- High structure, with features such as routines and visual schedules
- Exposure to children with typical development
- Promotion of generalization
- Measure progress and make adjustments

Focus of Interventions:

- Functional communication
- Social skills, including joint attention, imitation, and interactions
- Reduction of maladaptive behavior
- Cognitive skills, including symbolic play and perspective taking
- Adaptive and academic skills

Significant Scientific Interventions Supported by Evidence:

- Early intensive behavioral intervention programs
- Applied behavior analysis (ABA), including Discrete Trial Training (DTT) and Functional Communication Training (FCT)
- Cognitive Behavior Therapy (CBT), especially self-management
- Social skills training, including peer-based strategies, social stories, and social skills groups
- Visual supports and schedules
- Picture Exchange Communication System (PECS) when taught through ABA strategies
- Medication for attention, mood, aggression, and rigid behavior

Promising or Emerging Treatments:

- TEACCH - Treatment and Education of Autistic and related Communication - Handicapped Children
- Technology-based treatments, using computers or other electronic devices
- Music therapy
- Developmental relationship-based therapies, such as Floortime

Treatments with Limited Supporting Scientific Evidence:

- Sensory Integration (SI) Therapy
- Gluten and casein-free diets
- Facilitated communication
- Auditory integration training
- Most complimentary-alternative medicine interventions

Treatments Not Recommended:

- Chelation
- High doses vitamin supplementation
- Secretin
- Avoidance of immunizations

Other Aspects of Care for ASD:

- “Medical home” to ensure care coordination, parent training, and family support
- Medical care to manage problems with seizures, gastrointestinal problems, dietary imbalances, or disrupted sleep patterns
- Medications for specific symptoms
- Targeted therapies, such as speech/language and occupational therapy, to increase communication skills to improve independence in activities of daily living
- Family Support
- Support the independence of adults through job training and interventions to improve social-emotional adjustment

Challenges and Opportunities in Iowa:

- Early Identification

- Resources for families to help navigate the system
- Better coordination of services
- Intensive early intervention throughout the state
- Improved availability of Applied Behavioral Analysis (ABA)
- Insurance coverage
- Transition to adulthood, including job training and social-emotional support

Jack Willey commented that he would be interested in hearing more on autism at a future date.

CO-OCCURRING INTELLECTUAL DISABILITIES AND BEHAVIORAL ISSUES

Dr. Joel Ringdahl, Assistant Professor in the Department of Pediatrics and a key part of CDD's bio-behavioral services for years, presented on Co-Occurring Intellectual Disability (ID) and Behavioral Issues.

Statistics:

4-10% of individuals with ID exhibit self-injurious (self-directed aggression) behavior
7-25% of individuals with ID exhibit aggression directed at others

It is likely that if you work with the population of individuals with ID, you will encounter destructive or self-destructive behavior. It is even more likely to be encountered in the population of individuals with ID who are receiving residential services.

Questions:

- What is needed to build community capacity to be able to serve people with intellectual disabilities and behavioral or mental health issues?
- Are there better ways to support families and group home staff who are the caretakers?

Joel offered three answers:

1. Communication
2. Consistency
3. Crisis planning

1. Communication:

- Treatments often focus on teaching individuals to communicate
- Also need to emphasize communication among care providers including:
 - Parents
 - Day programs (schools, workshops, jobs)
 - In-home providers (respite and supported community living)
 - Residential service providers (community-based and facility-based)

Joel shared examples from the clinic:

- A residential facility refers the client, but no one from the facility comes to the appointment, instead the (adult) individual comes with parents
- The service provider who attends the appointment has no knowledge of what happens in other settings
- An attendant brings the patient without any information about the reason for referral

Proposed solutions:

- Integrated meetings
- Information sharing
- Taking a collective approach and sharing what has worked and what has not worked

2. Consistency:

- Consistency of contingencies – contingencies need to be similar across settings and care providers
- Behavioral “free lancing” should be avoided, especially when a behavior program is already in place

Proposed solutions:

- Integrated meetings
- Taking a collective approach and sharing what has worked and what has not worked
- Persistence with a plan – don’t give up too quickly

3. Crisis planning:

- Capacity to handle behavioral crises is limited
- Psychiatric units are perhaps the only option
 - Stay is usually short (2 to 3 days)
 - Focus is on stabilization, not program development
 - May not be the appropriate context because there are diminished expectations and no access to preferred activities
 - Staff may be unfamiliar with ID/DD
- Crises for people with ID are more chronic than acute
- An unfortunate strategy of handling crises is displacing the individual

Proposed solution:

- A system of crisis management options should be developed and exist along a continuum – we have some efforts, including IPART, but not a full continuum
- Comprehensive system-wide training related to development of functionally relevant behavior programs in an effort to decrease chronic and acute crises

Training:

- There is a high degree of turnover for care providers

- New staff need to understand how to work with each individual and their behavior plan

Proposed solutions:

- Program (individual) specific training
- Background education/training in behavioral principles and their application
- Higher pay and valuing care provision

IMPACT OF COMMUNITY CIRCLE OF CARE ON CHILDREN AND FAMILIES

Vickie Miene shared information and family stories on the impact of the Community Circle of Care (CCC) project on children and families. The CCC model of care combines medical assessment and social supports and utilizes family team meetings to bring everyone together

She started with a family story of an 11 year old boy called “Brady,” who was diagnosed with attention deficit disorder with hyperactivity (ADHD), oppositional defiant disorder (ODD), epilepsy, and pervasive developmental disabilities (PDD). He presented serious safety concerns and educational problems. CCC utilized:

- Family team meetings
- Care coordination services
- Comprehensive health exam and social history
- Psychiatric diagnostic interview via telehealth
- Medication management via telehealth
- Respite services

The total cost for the CCC services was a little over \$6600. If he had been placed in a PMIC (Psychiatric Medical Institution for Children), which was a likely outcome at the time he came to CCC, and stayed for the 256 average length of stay at a cost of \$176 per day, his public services would have cost \$45,584. Vickie share three more family stories that each resulted in a significant cost savings using the system of care model as opposed to facility-based or residential treatment. The total estimated cost savings to the system for the four cases is over \$115,000.

A comprehensive chart review of 1016 CCC children and youth found that if they had not had access to CCC services, 57% would have been in a higher level of care (more costly and more restrictive):

- 138 would have been in an out of home placement
- 117 would have been involuntarily committed
- 120 would be in the DHS child welfare system
- 208 would be involved in juvenile court services

Representative Heaton commented that what the Community Circle of Care and similar models is doing is right and very successful. He said he would like to see it replicated across the state.

Vickie added that a true system of care has a set of 10 values and principles that must be adhered to, although sometimes the term “system of care” is used more loosely. She said families have to be the ones to let others know what works and what doesn’t, and that local commitment and community partnership is vital. There is a state System of Care Resource Team and one of the suggestions is to create guidelines or rules to define what a true “system of care” is and what it is not.

Jack Willey thanked Bob Bacon and the CDD staff for their hospitality and informative presentations.

PUBLIC COMMENT

No additional public comment was offered.

ADJOURNMENT

The meeting was adjourned at 3:20 p.m. The next meeting is scheduled for July 21, 2011 at Iowa Lutheran Hospital in Des Moines.

Minutes respectfully submitted by Connie B. Fanselow.