Connection

A Newsletter from the Iowa Office of Consumer Affairs

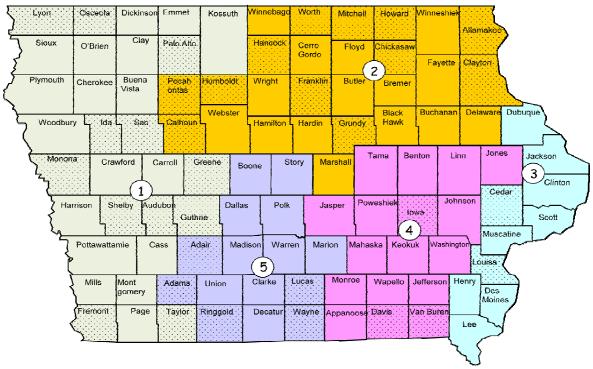
Summer 2011

An Introduction To The Office Of Consumers Affairs

The Office of Consumer Affairs offers a variety of services and supports to persons and families with behavioral health recovery and disabilities challenges, other state agencies and providers. The Office of Consumer Affairs will:

- Serve as a statewide resource for information, referrals, community education, individual education, one-on-one problem solving and system navigation
- Provide input on the development and implementation of policies and programs impacting behavioral health services and systems in Iowa
- Provide an advocacy voice to stakeholder groups throughout the state with the goal of promoting awareness of the concerns, perspectives and vision of persons and families with behavioral health recovery and disabilities challenges
- Assist DHS staff and contractors with disseminating information and gathering feedback from end users of behavioral health services and systems in lowa

Each of the five DHS service areas (see DHS Services Areas map below) will be served by a Regional Coordinator with further support offered by regional Advisory Committees comprised of persons and families with behavioral health recovery and/or disability experience. The Office Director and a statewide Advisory Committee will function to consolidate the activities of regional committees and coordinators.



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Who We Are

District 1 - Braden Daniels, Council Bluffs



I am honored to be representing the people of Region One. I am all too familiar with the concerns of those in the mental health community as I myself struggle with Bipolar Disorder and PTSD. I am passionate about giving people a voice and being an advocate. Suffering with a mental illness certainly has its challenges. Not knowing when an episode will occur, not knowing how long it will last, and wondering if you'll make it through to the next one are just a few of the struggles we face.

I have experienced firsthand the horrors of living with a mental illness. For years I went untreated. This caused me to make a lot of bad decisions. I would spend money

on frivolous tangents; I dealt with anger issues and many times would sabotage not only others' lives but my own as well.

Thankfully, there is good news! Recovery is possible! After being diagnosed in 2004, I started a treatment plan that took me to a better place. It was slow and hard at first. Originally, I would not take medications but did seek the help of a therapist who helped me to understand how my mind was working. We discussed ways of altering my perception of reality as I grew to understand it.

I was the kind of person with so much passion for life that I would dive in headfirst without considering the consequences of my actions. The therapist was helpful in getting me to channel that enthusiasm and I gained patience to help me make better decisions.

She convinced me to try a medication regimen that would not fix me, but might help to stabilize my condition. I was hesitant, but decided to try it. It was hard at first, finding the right medications and sticking to them, but I found that the combination of therapy and medication made all the difference in the world.

I stand before you a changed man. I now have a WRAP plan, I have gone through Intensive Psychiatric Rehabilitation (IPR), I am a 2010 graduate of the Iowa Peer Support Training Academy, and now... a Regional Coordinator for the Office of Consumer Affairs.

Prior to this, I was a minister for 15 years graduating with a Doctorate of Divinity. I have started two churches, counseled hundreds, been very active in the communities I've lived in and officiated many weddings and funerals. My depth of experience and passion for those in need makes me proud to serve in this new capacity.

Together with you, I hope to provide adequate resources and opportunities for those of us in the mental health arena because this is also part of MY recovery. Thanks for the opportunity and don't hesitate to contact me if you have any questions or concerns.

District 2 - Jim Paprocki, Waterloo



Jim Paprocki was raised in a northwest suburb of Chicago. He is active in his church, currently serving on the church Board, and has served on other committees. Jim has been married to Martha for 25 years, and the couple has 2 sons. Jim and Martha's younger son has a diagnosis of autism. Parenting a child with autism was the inspiration for Jim to become involved in the independent living movement.

Jim received a Master of Public Policy degree from the University of Northern Iowa. He has worked as a union activist and in numerous positions in human services. This includes being a supervisor of direct care professionals in Home and Community-Based Services (HCBS). The goal was to empower people with behavioral health issues to maintain independence. He

is now retired based on a permanent medical condition.

Jim struggled with his own behavioral health and recovery issues. He currently acts as a facilitator for the *Living Well with a Disability* workshop, a nationally recognized health and wellness training, developed in consultation with the University of Iowa, and the Centers for Disease Control and Prevention.

Jim is a dedicated advocate for personal choice and inclusion for people with disabilities. He has demonstrated vision and leadership as a Governor-appointed member of the Iowa Statewide Independent Living Council, and on the Olmstead Consumer Taskforce. Jim also has written several Guest Opinion pieces for the *Des Moines Register*, including the need for State funding of the Iowa network of Independent Living Centers, and on providing independent living services consistent with the 1999 U.S. Supreme Court Olmstead decision.

District 3 - Todd Noack, DeWitt



In my recovery process, I have learned that I can live my life even with chronic pain and depression.

My story begins back in 1996, when I first hurt my back. I worked in a rent-to-own store managing customers' accounts. I had to go visit clients at their homes to find out why they had not been in contact with me. There were times when I would have to pick up the merchandise alone. I thought I was unstoppable but later found that I was not. One day while working I bent over to pick up a pillow from a couch set. When I was standing up, I fell to the ground. I soon found that I had a

herniated disc in my back. The doctor told me I needed to find some other type of work but I was in line for a promotion and went against the doctors orders. I told my employer I was fine.

Through the years I was unable to heal because I refused to take care of my body. One morning in 2006, I was getting ready for work. I started to come down my stairs and fell to the floor in the most agonizing pain imaginable. An ambulance came for me and took me to the hospital were they gave

me large amounts of pain medicine. I was about to get released but when they tried getting me off the table, I could not move. They admitted me and found the herniation had turned into a deterioration of 2 discs. They did a procedure called a discectomy that was intended to release some of the pain. One of the restrictions was to not lift heavy objects but under a year later I was in the hospital again for the same procedure. They had tried cortisone shots in my spine but after a while they began not to work as well. I asked my pain doctor if there was any type of support group for folks with chronic pain and neither he nor the social worker said they knew of any. My reaction was "you've got to be kidding me!" After the second surgery, the doctor told me what I really needed was to have a fusion of the 2 discs. The problem with that was he would not do it because my weight was over 350 pounds.

In 2009, I went to my family doctor because the pain and numbness was getting worse. He sent me to the University of Iowa where I met with a spine surgeon. They told me the same thing that the other surgeon did. I needed to have the discs fused. The things that he suggested were more promising. He wanted me to work with him, a dietician, and a doctor in weight loss. Things were looking up. They put me on a diet medication, some pain medication, and I had a goal of losing 100 pounds.

Around seven months in, I had some problems. I was getting tired of the pain, feeling worthless as a father for not working, and the weight just was not coming off fast enough. I told myself that my family would be better off without me. Like many people with chronic pain, I started to experience depression. I took an overdose of my diet and pain meds. I woke up in intensive care the next day mad at everyone for not letting me just die. They sent me to the psych ward, where I found a spiritual guide who told me where I was. When I got out I started using my resources like my pastor, friends from church and just talking every day. I woke up in pain and made it a good day, the days I woke up in less pain I made it a great day. In May of 2010, I had reached my goal. I was at 218 pounds and felt good about who I was and had a date for my surgery. It's been almost a year now after the surgery. the pain is worse and I am on disability but I am now a Peer Support Specialist, on the IPSTA Advisory Committee, working on a project with Magellan health care, and I am the Regional Coordinator for Consumer Affairs. I still have daily depression but now I am able to help others and show them the hope through my story and my accomplishments.

District 4 - Rhonda Shouse, Cedar Rapids



Hi. My name is Rhonda Shouse and I live in Cedar Rapids. I have two daughters – 18 and 22 years of age. I personally have dealt with mental health issues since I was a teenager and my youngest daughter also has a mental health diagnosis. I'm originally from Ohio, just north of Cincinnati. I've lived in Iowa for 21 years.

I have been a newspaper reporter for *The Cedar Rapids Gazette* and *The Iowa City Press Citizen*. My journalism skills have been extremely handy as I needed to locate mental health resources for myself and my daughter.

My journey to dealing with my mental health issues began six years ago when I was diagnosed with major depressive disorder and generalized anxiety disorder. Prior to that, I suffered in silence with my depression even after two suicide attempts as a teenager. I grew up in a family that didn't

talk about those types of things. After another suicide attempt in 2005 I got help for the first time. I was signed up for a partial hospitalization program at a local hospital and completed that successfully. I left the program with much more knowledge about how to stay healthy mentally. I have continued to work to stay healthy by completing other programs such as STEPPS and WRAP.

What pushed me into advocacy work however, were my daughter's mental health issues. In 1996, she was diagnosed with ADHD at the age of three. Over the years her diagnosis has changed tremendously. She now is diagnosed as having Bipolar Disorder with psychotic features, ADHD, and Asperger's Syndrome.

My personal experiences were one thing, but I quickly learned that lowa's childrens mental health care system is fragmented at best. The education I gained from being her "case manager" has allowed me to help other families in similar situations. As I talked with parents I realized that there were a lot of families that didn't have someone who could understand their situation to offer them support.

Four years ago I decided to quit my job and stay home to better help my daughter. At the time I was getting phone calls from school regularly about behavior issues. As her treatment team figured out a better combination of medications for her there were fewer disruptions and school and my day time started freeing up. I decided I wanted to be involved in creating positive change in lowa's overall mental health care system. Over the past four years I've been involved with numerous organizations including Iowa's Mental Health Planning Council; NAMI Linn County, NAMI Johnson County, NAMI Iowa; and the Iowa Empowerment Conference. I also started a parent support group with NAMI Linn County and began teaching a class for parents of children with mental health issues.

I look forward to working as a regional coordinator with the Office of Consumer Affairs because of the opportunities it will provide to help people living with mental illness and their families. Receiving help from people when you're in a bad spot with your mental health is good, but being able to be a person to provide that help is the greatest gift I can ever imagine giving.

<u>District 5 - Lisa Robin Sanford, Des Moines</u>



I am a Native American/European resident of Des Moines, lowa. My diagnoses in the mental health systems have been many over the years, however, I connect to having severe P.T.S.D. and addiction. I have also overcome brain injuries. I am 46 years old, and my first diagnosis came at the age of 9. I have been in recovery since October 2007.

Today, my life is amazingly different and productive, as I have undergone miraculous transformations through rehabilitative services, education, and provisions through waivers, case management and supported community living. I am a full-time student at DMACC, and am employed by Iowa Advocates of Mental Health Recovery as a Consumer Family Experience Team researcher and advocate. I am also District 5 Regional

Coordinator for the Office of Consumer Affairs.

The advocacy that I am involved in are on all levels: personal, individual, local, state, national, and federal. I write, do speaking engagements, and participate with other groups that are involved in advocacy. My heart's passion evolves around systemic positive change in our mental healthcare provisions and policies. I believe every individual has a right to receive effective care that leads to a high quality of living, and deserves opportunities to truly reach their desired goals within the community.

For me, mental health is not problematic or a revelation of one's ill character. It is a treatable condition that can be managed. We can be full of hope, inspiration, and the amazing qualities of individuals who are living with challenges. Our challenges are a part of our lives, yet do not dictate our identities or limit our endless possibilities....

Director - Todd Lange, Dubuque



Five years ago, Todd Lange fueled his recovery from depression and anxiety through service to NAMI and the peer-run Wellness Center in Dubuque. Todd credits his ongoing recovery to building connections with others and finding purposeful work.

"I've learned along my recovery path the power and importance of nurturing my whole person, body, mind and spirit. Diet and exercise, connection with people I love and care about, and doing work that helps to improve the lives of others have all been key to my ongoing recovery."

Todd is one of the founders of the Iowa Advocates for Mental Health Recovery and currently serves as the Director of the Office of Consumer Affairs. He is in the second year of marriage to advocate and crisis counselor Carolyn Pettit-Lange and loves spending time walking along the Mississippi River, cheering for the Hawkeyes or spending time with his nephews. History and democracy are his other passions.

We Want To Hear From You!!

The Office of Consumer Affairs needs your voice! "Nothing about us, without us" means that we need to hear from YOU in order to make the **OCA** newsletter and this organization a powerful force



for the healing and recovery of individual people and the healing and recovery of our local and state behavioral health service systems. Please consider sharing your news, thoughts, inspirations, dreams, recovery tips, creativity and more with our editorial and publishing team. All you need is a heart that wants to share, and some way to get the sharing to us! We'll accept audio and video tapes (we could put your short home-made film or blog onto the website version of the newsletter), emails, attachments, handwritten letters, artwork in many forms and the list goes on! If you're interested in joining our team or making a contribution to **OCA**, contact Todd Lange, Director at 1-877-OCA-IOWA or tjlange@dhs.state.ia.us.

Peer Support In Iowa

In 2006, the Division of Mental Health Disability Services (MHDS) put out a competitive bid to create a training academy to nurture the development of peer support services in our state. It was based upon some very exciting work that had begun in the State of Georgia under the direction of the Georgia Office of Consumer Affairs. At the time, few in our State had heard of Peer Support as a mental health and recovery oriented service. We didn't know how much interest there might be from providers of mental health services and people in recovery for developing what has become known as the Iowa Peer Support Training Academy (IPSTA). A great deal has changed since that time, and there has been a real shift in our State toward practices and supports that help to move people with mental illness meaningfully toward their own recovery!



(I ot r) DHS Director Chuck Palmer and Spring 2011 IPSTA graduates Kathi Doiel, Charlotte Ellwanger, Anna Linnell, Tara Talbert, Loula Tesfai, Victoria Oestmann, Judy Perry, Teresa Green (not pictured) Peer Support services have grown tremendously in Iowa and across the nation. Now an evidence based practice recognized by the Substance Abuse and Mental Health Services Agency (SAMHSA) and the Centers for Medicaid and Medicare Services (CMS), Peer Support services are Medicaid billable in Iowa and at least 26 States around the country.

In Iowa, Peer Support services are authorized through our managed care entity, Magellan Health Services. At present, there are 13-15 mental health providers billing Medicaid for Peer Support services. Graduates of the Iowa Peer Support Training Academy are working as Peer Support Specialists within those programs.

This year, the Division of MHDS hopes to release another competitive bid to fund the Iowa Peer Support Training Academy (IPSTA) for the next several years. The Advisory Committee of the IPSTA is also working

with the Division of MHDS, Magellan, and the Iowa Board of Certification to develop criteria for the certification for peer support specialists in Iowa.

A national meeting centered around "The Pillars of Peer Support," was held at the Carter Center in Atlanta, Georgia, where the Georgia Model of Peer Support was born in November of 2009. The assembly of twenty-six States put together a list of 25 key elements to be used as goals in States seeking to develop evidence-based peer support services. One of those pillars of peer support services says, "A state's Peer Specialist Program is strengthened when...there are unifying symbols and celebrations that give Certified Peer Specialists a sense of identity, significance and belonging to an emerging profession or network of workers."

During this year's "Recovery In Iowa" conference, we recognized the graduates from the Spring 2011 Iowa Peer Support Training Academy as the photo above demonstrates! These 8 graduates join 104 other Iowans in recovery who have graduated from IPSTA since 2006. Peer Support is growing yet we need your continued advocacy to ensure people in recovery continue to use their lived experience to support one another into the future. A recovery-based system takes many pillars to stand with strength!

Family-Driven Defined

"Family-driven" means families have a primary decision making role in the care of their own children as well as the policies and procedures governing care for all children in their community, state, tribe, territory and nation.

This includes:

- ⇒ Choosing culturally and linguistically competent supports, services, and providers
- ⇒ Setting goals
- ⇒ Designing, implementing and evaluating programs
- ⇒ Monitoring outcomes
- ⇒ Partnering in funding decisions

Guiding Principles of Family-Driven Care

- 1. Families and youth, providers and administrators embrace the concept of sharing decision-making and responsibility for outcomes.
- 2. Families and youth are given accurate, understandable, and complete information necessary to set goals and to make informed decisions and choices about the right services and supports for individual children and their families.
- 3. All children, youth, and families have a biological, adoptive, foster, or surrogate family voice advocating on their behalf and may appoint them as substitute decision makers at any time.
- 4. Families and family-run organizations engage in peer support activities to reduce isolation, gather and disseminate accurate information, and strengthen the family voice.
- 5. Families and family-run organizations provide direction for decisions that impact funding for services, treatments, and supports and advocate for families and youth to have choices.
- 6. Providers take the initiative to change policy and practice from provider-driven to family-driven.
- 7. Administrators allocate staff, training, support and resources to make family-driven practice work at the point where services and supports are delivered to children, youth, and families and where family and youth run organizations are funded and sustained.
- 8. Community attitude change efforts focus on removing barriers and discrimination created by stigma.
- 9. Communities and private agencies embrace, value, and celebrate the diverse cultures of their children, youth, and families and work to eliminate mental health disparities.
- 10. Everyone who connects with children, youth, and families continually advances their own cultural and linguistic responsiveness as the population served changes so that the needs of the diverse populations are appropriately addressed.

Contributed by: Iowa Federation of Families for Children's Mental Health

106 South Booth Anamosa, IA 52205
Phone (319) 462-2187 · Toll Free 888-400-6302
· E-Mail: help@iffcmh.org · Website: www.iffcmh.org

Remedial Services Moves to Magellan Health Services of Iowa on July 1

The name will change to Behavioral Health Intervention Services (BHIS). For more information go to www.magellanofiowa.com and click on "For Providers" and select "Behavioral Health Intervention Services" or call 800-638-8820.

IOWA DEPARTMENT ON AGING

PRESENTS

A CONVERSATION ON AGING ISSUES

The lowa Department on Aging is holding community conversations across the state this summer to give you an opportunity to learn about resources for older lowans and voice your concerns about issues facing older lowans. This is also an opportunity to discuss HF45, the legislative mandate to reduce the number of Area Agencies on Aging. **Everyone is welcome.**

- RETIREMENT
- CAREGIVING
- TRANSPORTATION
- HOME HEALTH CARE
- HEALTHY LIVING

- NUTRITION
- HOUSING
- ABUSE & EXPLOITATION
- COMMUNITY INVOLVEMENT
- EMPLOYMENT

Date	Time	Town	Location
July 7	12:30-2:00 4:30-6:00	Mt. Pleasant Ottumwa	City Library, 307 E. Monroe St. Salvation Army Center, 725 W. Main St.
July 11	2:00-3:00 5:00-6:30	Coralville Toledo	Public Library, 123 S. Linn Street Community Bank of Toledo, 100 E. High St.
July 26	12:30-2:00 5:00-6:30	Storm Lake Sioux City	Middle School Media Center, 1811 Highland Dr. Morningside Library, Garretson Room, 4005 Morningside Ave.
July 28	12:30-2:00 5:00-6:30	Atlantic Creston	lowa Western Community College, 705 Walnut Southwestern Community College, Highway 25/Towline Street
August 2	12:00-1:30 4:30-6:00	Calmar Cedar Falls	Fire Station Meeting Room, 102 S. Charles Public Library, 524 Main Street
August 4	12:30-2:00 5:00-6:30	Carroll Ankeny	Chamber of Commerce, 407 W. 5 th Kirkendall Public Library, 1210 NW Prairie Ridge Dr.
August 9	12:30-2:00 4:30-6:00	Dubuque DeWitt	St. John's Episcopal Church, 1458 Locust St. The DeWitt Community Center, 512 10 th St.
August 11	12:30-2:00 5:00-6:30	Mason City Webster City	Public Library, 225 2 nd St. SE Kendall Young Library, 1201 Willson Ave.

For more information, call 800-532-3213 or e-mail www.aging.iowa.gov

These meetings are accessible to individuals with disabilities. If you have special needs, please notify us using the contact information above.



The Iowa Empowerment Conference Presents:

Reaching to Recovery

A consumer led conference for individuals, families and youth dealing with mental health issues

Tuesday, Wednesday, Thursday August 9th, 10th, and 11th, 2011

> Airport Holiday Inn 6111 Fleur Drive Des Moines, Iowa

Stipend applications are due on Friday July 22nd.

For questions or a brochure contact Deb Williams at dwilliams906@hotmail.com or 641-753-7414.

Grand Opening Alert!!



The Phoenix Center 905 Montgomery Street Decorah, Iowa Wednesday July 13th, 2011 2 - 8 pm

- Enjoy Root Beer Floats
- Explore Peer Support Services
- Experience The Phoenix Center at Northeast Iowa Behavioral Health

The Phoenix is open from 2 to 8 pm from Monday through Thursday in Decorah and offers:

*Peer Support * Internet Terminals * Resource Center * Games*

For more information call 563-382-3649



Keep It On Your Radar

Mental Health System Redesign

Adult Disability Services Redesign legislation has recently been passed by the Iowa General Assembly and is awaiting the signature of the Governor. This legislation changes the Mental Health System in Iowa from a county-based system to a regional system replacing "legal settlement" as a basis of determining how an individual is funded for services. In addition core services will be indentified, crisis services will be implemented statewide, approaches will be sought for seamless co-occurring services and addressing brain injury. As part of this process, workgroups will be established by the Department of Human Services so people with lived experience and family members can consult on this transformation. To understand the workgroup structure, view the diagram on the following page. The workgroups will report to an Interim Committee and work throughout the summer and fall. The resulting recommendations will be given to the 2012 General Assembly. If you are interested in becoming a member of a workgroup contact Theresa Armstrong at the Department of Human Services at TArmstr1@dhs.state.ia.us or 515-281 -3780.

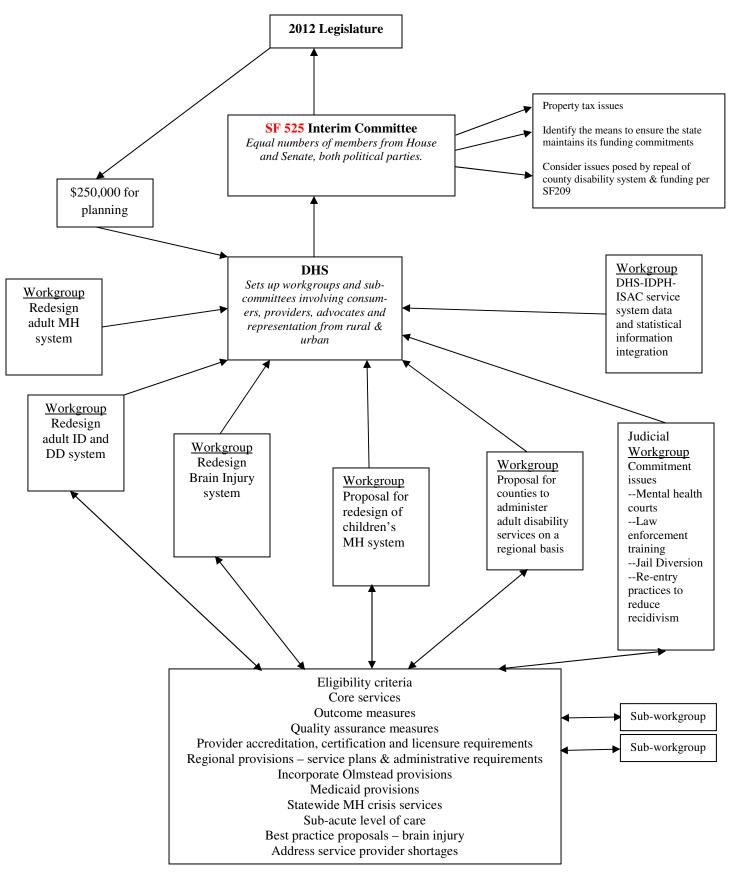


Legislative Resouces

Iowa General Assembly Website: www.legis.iowa.gov

Find you local Legislator: www.legis.iowa.gov/Legislators/find.aspx

Workgroup Structure





855-OCA-IOWA www.ocaiowa.org tlange@dhs.state.ia.us

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Lisa Robin Sanford

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Upcoming Events

July 8th

Olmstead Consumer Taskforce

10:00 am - 3:00 pm

Pleasant Hill Public Library, Pleasant Hill

July 16th

Mental Health Planning Council

10:00 am - 3:00 pm United Way, Des Moines

August 9 - 11

Empowerment Conference

Airport Holiday Inn, Des Moines (641) 753-7414 or debwilliams48@yahoo.com

October 11 -12

Mental Health Conference

Scheman Building at Iowa State, Ames (515) 309-3315 or info@trainingresources.org

