

Good afternoon, I..... am Alex's mom. Alex is 14 years old and has PTSD, ADHD, RAD, Anxiety, Severe Sensory Integration issues, Asperger's, and ODD. We adopted Alex from Russia 12 years ago, when he was about 20 months old. We knew when we adopted him, that there was going to be a big chance that he could have severe issues, and we were ready to take on the challenge, and raise him with pure love and support throughout his life.

At age 4, we were able to diagnose Alex with ADHD, and already he was showing signs of PTSD, RAD, Anxiety, and several sensory integration issues. We took him to Dr.'s and Clinic's all over the United States including UIHC Child Psych, Center of Disabilities and Development, Circle School, Adoption and Attachment Clinic, Witwer, Psychologists, Psychiatrists, the Neurological Development Clinic in Oregon, 4 Oaks, and the University of MN International Adoption Clinic. During this time around age 7, Alex was placed on the Ill and Handicap waiver per suggestion of the Center of Disabilities and Development. A couple of years later, he was switched to the Children's Mental Health Waiver as they thought it was a better fit for Alex's diagnosis. With the CMHW, we were provided with counseling, individual and family, respite care, secondary TIX insurance, as well as many other supportive measures emotionally and financially, that we truly needed and appreciated.

Despite our best efforts and unconditional love, in May of 2009, Alex was admitted to 4 Oaks PMIC in Cedar Rapids. As parents, it was our last option. As hard and heartbreaking as it was, we knew we had to do what was best for Alex, and not what was best for us. Once inside 4 Oaks, no one explained to us that if he stayed there we would lose his CMHW, and not get it back when he was discharged. It wasn't until we started to plan his discharge in March 2010, that we were told that, "Oh, you should have put him back on the waiting list, right when he came in!"

Alex worked hard during his time at 4 Oaks. He was there for 13 months, and it not only helped Alex but our entire family as well. Here lies the problem. Alex was discharged on June 30, 2010, with no CMHW services. He came home with no counseling, individual or family, no respite, no help, for the transition. We totally felt like when we needed the help the most, in bringing him home and helping our entire family with the transition, WE GOT NOTHING!!! The only thing I was able to fight for was to keep his secondary insurance TIX, to help cover medical and medication expenses.

Today, Alex remains on the waiting list. 18 months later, he is still on the waiting list. While we need aftercare and support, he is still on the waiting list. He is regressing, he needs support, we need support, we need counseling, we need respite,

and he is still on the waiting list!!!!!! My biggest question throughout this ordeal is, why, why, why, you would not hold a spot for a child when admitted into a PMIC. I really feel like we were set up to fail. Have you ever had a child with the CMHW go in that did not qualify when he/she came out? Wouldn't you just review it when he/she is ready to be discharged? I don't get it, and I never will.

The way the system is currently set up, what is the incentive for families not to readmit these children when they have lost all hope and resources? The state pays for the care when the children are inpatient at a PMIC, and it has to be much more costly than putting them back on the CMHW.

Please, reconsider how this waiver is set up. Please, consider reviewing and changing your policies. Please, don't set anyone else up to fail, like Alex was, because he is a kid who deserves a break for once in his life. His life shouldn't have to be this hard, and unfortunately he isn't the only one who is suffering, I know, I have seen the faces, the tears and pain in their eyes.

Sincerely,

Alex's mom

Angela H. Greiner

[REDACTED]  
West Chester, IA

52359  
[REDACTED]



Hi, my name is Cynthia and I am 18 years old. I was first hospitalized for my mental health when I was 8 years old. Growing up was difficult. When I was younger the word 'No' was a constant trigger. I would have horrible fits and sometimes this would lead to more hospitalizations.

In school I was made fun of and I had a hard time socializing. I also did not have a chance to make friends because I was constantly moved to different out of home placements. I missed out on good high school memories, including high school homecomings.

By the age of 14 I had had dozens and dozens of out of home placements. At the age of 16, I was told that no program in the state of Iowa would accept me, so I was placed out of state. I spent a year in a treatment facility in Missouri. When I was 17 I graduated from that program and was sent back to Iowa to another treatment facility. Finally, on December 10, 2010, the day before my 18<sup>th</sup> birthday, I was released to live in the community.

With lots of services and supports, I have been living in the community for almost a year. Although I have had short hospitalizations, I have been able to get back into the community and I have not had any long-term placements.

I now have my own apartment and I love it! I have someone help me with cleaning, money management, and medication assistance. I also see a counselor and a psychiatrist. I have a worker that checks up on me and a case manager who helps me get any services I need. I also have Community Circle of Care who helps both me and my family meet other youth and families who have kids with mental health challenges. I am finding out there are lots of other youth out there like me.

I now have lots of friends and I am a bit of a social butterfly! Now that I live in the community, I finally feel like I can be myself.

If I were given the opportunity to talk directly to individuals who can help kids stay in their community I would say "look what I have been through!". Please help kids stay near their families and in their communities.

If I were given the opportunity to talk directly to youth who are placed out of state I would read them my poem:

Thank you for listening to my story.

***A fairytale becomes a dream,  
a dream becomes a goal,  
a goal becomes a success,  
and a success I shall be.***



Hello. My name is Harley and I am from Northeast Iowa. I was about 7 years old when I first got involved in the mental health system. At that time I was hospitalized for one week. From that point on, every now and then I would cycle through a variety of placements throughout the state of Iowa. I had over 16 placements and throughout that time over 9 different diagnoses were added to my chart.

In 2008, my family was told that no program in the state of Iowa would accept me, so I was placed out of state. I lived in at a placement in Utah for about 10 months. At that time, the state said it was time for me to come back to Iowa.

That summer when I returned from Utah I went to live with my family, who at that time lived in Dubuque. For lots of different reasons we moved to Strawberry Point shortly after I returned home. It was an opportunity for me to start over. No one knew me, so it was a fresh start for me, especially at school.

I was able to make friends and I was surrounded by adults who gave me a chance. When I had rough days, I would go to the library, read a book, or go for a run. I came up with coping skills that helped me stay in school.

I currently have a psychiatrist who manages my medication and I have been able to stay in the community since June 2009. In May 2012 I will graduate from Starmont High School. I have already been accepted at Ellsworth Community College and I plan to major in renewable energy technology and minor in astrology. Life's pretty good. I now know people believe in me.

If I were given the opportunity to talk directly to individuals who can help kids stay in their community I would say please help youth stay close to home. The farther you are away the harder it is for your family to visit which can make you more depressed. You feel detached and youth may not want to start on their treatment.

If I were given the opportunity to talk directly to youth who are placed out of state I would say keep moving on. You will get better. Don't worry about the time it takes. People believe in you.

Thank you for listening to my story.

JAMI-Judicial Advocates for persons with Mental Illness

Date: 9/13/11

To: Dave Boyd-State Court Administration, Co-Chair Mental Health redesign  
Karalyn Kuhns-Dept. of Human Services, Co-Chair Mental Health redesign

Dear Co-Chairs:

I am writing on behalf of the Board of Directors for JAMI-Judicial Advocates for persons with Mental Illness. We represent the largest group of judicial patient advocates in Iowa. The purpose of this letter is to thank you for your participation in the workgroup and to request a JAMI member be approved to the committee.

At our Spring Conference in April, we elected Rose McVay, Scott County advocate, to serve as a liaison to the workgroup for mental health redesign. Rose is active with our organization and is familiar with several advocates throughout the state. She has years of experience and is well versed in the court process and individual patient's rights and needs. Rose would be an excellent asset to the workgroup. We are also appreciative of Polk County advocate Kelly Yeggy, a non member, providing information to our group.

It is our understanding that the workgroup is tasked with writing comprehensive mental health reform to be considered next session that may greatly impact patients and advocates across the state. We consider Rose to be an excellent resource that would enhance your workgroup efforts. If you are in need of additional information, do not hesitate to contact me. Thank you for your time and consideration.

Respectfully,



Jackie Bailey  
JAMI Board Secretary  
Black Hawk and Grundy Co.  
Patient Advocate  
1407 Independence Ave;  
Waterloo, IA 50703  
(319) 292-2254

Mental Health Redesign, Public Hearing Sept. 23, 2011

✶ Jo Ann Finkenbinder

[REDACTED]

Cedar Falls

[REDACTED]

I am here to day representing the League of Women Voters of IA. I am the sentencing and corrections chair. In 2002 LWVIA adopted at our convention a study of the sentencing and corrections system in Iowa. The study lasted 2 years; a proposed position was put forth and sent to the local leagues. Local Leagues studied it as well and approved our proposed position. The LWVIA Board approved the position in 2005. We have been monitoring and lobbying on the justice position since then.

The position in part is: The LWVIA supports a justice system that is fair and protects the public safety. The LWVIA supports legislation that considers offenders with special needs. Some examples of offenders with special needs are the mentally retarded, mentally ill, geriatric inmates, and medically needy.

I am here to speak in behalf of our concern for the mentally ill offenders in prison.

**Facts:**

Dr. Bruce Sieleni, DOC Psychiatrist, reported as of March 2, 2010, there were 8,324 offenders in prison, 46.2% or 3,846 were diagnosed with mental illness that required ongoing psychiatric treatment.

In addition, 29.5% or 2,455 inmates met the criteria for being seriously ill. (Dr. Bruce Sieleni, report to the IA Board of Correction, May 2010)

In 2011, Dr. Deol, Medical Director for the IA Dept. of Corrections, reported there were 2 suicides in the prisons in 2010. (Dr. Deol, Jan.2011 report to the IA Board of Corrections)

In January 2011, Dr. Deol reported 44.6% of the offenders were on psychiatric medications.

**Recommendations:**

- LWVIA is asking the Dept. of Human Services and Dept. of Corrections Directors to work together to take measures to begin de-criminalizing mental illness in Iowa. Reports need to be made to the legislature on progress in this area. The Public Safety Advisory Board could be asked to act on this issue with a work group. Criminal and Juvenile Justice Planning should monitor progress in this area with periodic reports and recommendations. One measure of success would be the drop in the number of mentally ill in our prisons.
- A statewide jail diversion program must be established to divert offenders into the appropriate programs and to make recommendations to judges as to the best placement.
- Local mental health outpatient and inpatient services must be available and accessible in urban and rural areas. Inpatient services must be of adequate duration to ensure the patient will be able to function in the community at the time of discharge and that there is after care provided. These services must be available regardless of income.
- Iowa must address the shortage of psychiatrists including those specializing in child psychiatry, to ensure we have the needed medical supervision. In addition, Iowa must ensure that licensed mental health treatment professionals are available in urban and rural areas to provide therapy and counseling. Mental health professionals must be accessible 24 hours a day and crisis intervention services must be available statewide.
- The Department of Human Services and the Department of Corrections must partner in advocating for mental health parity for Iowa to ensure those families with insurance can be covered for mental health treatment.

Jo Ann Finkenbinder

LWVIA Corrections and Sentencing Chair

31 River Ridge Rd

Cedar Falls, IA 50613

**DRAFT PROPOSAL – by Mike Wood 10/24/2011**  
**Concerning Consumer/Family Value in Mental Health and Disability Services**

1. The State of Iowa each year receives approximately \$3.5 million in federal Mental Health Block Grant (MHBG) funding. These monies are provided by the Substance Abuse and Mental Health and Service Administration (SAMHSA).
2. There has been a precedent for the allocation of a portion of these funds to particular recipients. Currently, seventy percent of the MHBG dollars go to the Community Mental Health Centers.
3. The allocation methodology of monies from the MHBG may be subject to change based upon the regionalization of services under the redesigned system. SAMHSA will also be redefining appropriate uses of MHBG funds based upon language contained in their FY2012-2013 Block Grant Application.
4. The redesign workgroup process and the regional public forums have illuminated the benefit of adequate Consumer/Family participation in mental health and disability services. They provide a clarifying recovery voice and the delivery of services from their unique perspective.
5. Consumer/Family leadership will be essential in the monitoring of the new regional system. The Regionalization Workgroup has had discussions about the availability of Consumer/Family members on regional boards and panels. In 2009, SAMHSA began Statewide Consumer/Family Network Grants for the purpose developing leadership and enhancing sustainability of such organizations.
6. The Iowa Advocates for Mental Health Recovery (IAMHR), for example, was a recipient organization under a statewide network grant, which lasts until September 2012. With skills developed, IAMHR applied and received the Office of Consumer Affairs (OCA) post through Iowa DHS. Many Consumer/Family organizations have contributed to the redesign effort in isolating suitable core services and gathering voices.
7. It is apparent that ongoing Consumer/Family leadership and the related recovery service providers can be located, developed and nurtured through Consumer/Family driven organizations now existing in Iowa.
8. **It is requested that the MHDS Study Committee, DHS and the Full Legislature (in 2012) consider the allocation of Ten Percent of the full SAMHSA MHBG to statewide Consumer/Family organizations to continue the crucial effort of developing leaders and specific programs to enhance recovery and lower costs of mental health and wellness.**
9. **The Ten Percent will be though DHS requests for applications, such as, but not limited to, the following project areas:**
  - **The Iowa Office of Consumer Affairs.**
  - **Statewide Peer and Family Support Specialist leadership and staff training.**
  - **Statewide Consumer network organization infrastructure and sustainability.**
  - **Statewide Family network organization infrastructure and sustainability.**
  - **Stipend funding for suitable training by Consumer/Family organizations.**
10. **While further guidelines will need to be arranged, this funding mechanism through the MHBG will assure an ongoing healthy State-Provider-Consumer-Family interaction.**

Thank you for the opportunity to give input !!

### Talking Points

- RCF's provide an integral service in the continuum of care for persons with mental illness.
- In the past, RCF's were county homes and primarily provided services to persons with ID. Today RCF's primarily provide services to persons with mental illness.
  - ~~Not just~~ "ware housing as a term I have often heard"
  - Focused on shorter stays with emphasis on transition to the community
  - Treatment based approaches
    - Reduced length of stays
    - Decreased recidivism
    - Increased opportunities for success in the community
  - Treatment oriented approach
    - Skill development
    - Illness and medication education
    - Crisis intervention skills
    - Development of natural supports
    - Community integration

~~Almost and~~ informal care transitions model to increase opportunities to be successful in the community once they are ready

- Provide a wide range of consulting services to address multiple often complicated diagnosis
  - Psychiatrist
  - APRN with psychiatric certification
  - Individual Therapy
  - OT/PT
  - Family Practice
- RCF's need to be included in core services available to all Iowans with mental illness as much as we would like to have everyone live in their own home, not everyone can and some choose RCFs as their home.
- The RCF task force in 2010 reported 1,126 individuals with mental illness received services in RCF's in Iowa.
- The majority of people admitted to RCF's come directly from a psychiatric unit in a hospital (acute care) and are not ready to live independently in the community.
- RCFs not only serve as a transition point from acute care to community along the continuum, they also serve as an alternative to acute care when consumers require more care but not necessarily acute care

Deane Brecht RN MSN, Executive Director, Penn Center, Inc  
2237 245<sup>th</sup> St  
Delhi, Iowa 52223  
dbrecht@abbe.org

- The level of acuity of referrals to RCF's is increasingly more severe. Our RCF has adapted to the changing needs of individuals we serve and will continue to do so as their needs change.
- There is a need for a higher level of care than RCF's provide (sub-acute care) however there are currently no regulations that fit this model. This would reduce the length of stay in hospitals and other acute care settings (MHI's).
- Funding for RCF services is a major concern.
  - Currently, counties are the primary funding source.
  - Concerns regarding non-medicaid individuals needing service

RCFs continue to adapt to the changing needs of individuals with mental illness and other disabilities.

- Are an important part of the continuum of care in Iowa.
- I support change, however, I encourage the workgroups to include RCF level of care in the core services
- 

*Diane Brecht RN MSN  
 Executive Director  
 Penn Center, Inc  
 2237 245th St  
 Delhi, Iowa  
 52223*

*dbrecht@abbe.org*



## **PRAIRIE VIEW MANAGEMENT, INC.**

18569 Lane Road \* Fayette, Iowa 52142 \* (563)425-3291 or (563)422-5606 \* FAX (563)422-5607  
e-mail – pvmi@netins.net

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\*Residential Care \*Community Living \*Respite Care \*Employment Related Services

October 2011

To: MHDS Redesign Work Group Members & Legislators

My family has been touched first hand by mental illness, Traumatic Brain Injury, Prader Willi Syndrome and Substance Abuse.

I am and have been a RCF administrator of Prairie View Management Inc., Fayette, a 90 bed facility, for 23 years. Our facility is at maximum capacity and has been for several years.

Prairie View clients are evolving through our program, as they gain skills in an average of 9 3/4 months from admission, and 65% are discharged to more independent living situations. Our population is primarily made up of persons with Chronic Mental Illness (CMI). Most Prairie View clients are under mental health commitment. Many are being treated for substance abuse problems, are under probation, some have intellectual disabilities, or (self-)abusive histories. All of them have been certified by a physician as needing 24 hour care and supervision. They are not the people who should become homeless or discharged prematurely to home.

Prairie View, like many other RCF's (besides providing 3 meals and a bed) provide individualized Program Planning which includes transition planning from the day of admission, where appropriate. RCFs provide an integral service in the continuum of care for people primarily with chronic mental illness. Pre-vocational or vocational issues are addressed and services provided at no additional cost to some clients who have those needs. Clients who are appropriate are receiving habilitation services or waiver services, to access federal \$ while in RCF.

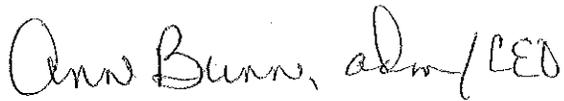
RCFs like Prairie View provide jail diversion programs, but we haven't used that term. We take the people the county and Department of Corrections refer who they determine would do better in our program than in a correctional facility.

90% of the clients who were admitted to Prairie View came from a higher level of care in 2010. (83% in 2009) Prairie View had 217 referrals in 2010 and only room to admit 80. (We were often full.) SEE ATTACHED CHARTS and notations made at the end of the years regarding the psychiatric hospitals, MHI, & Dept. of Corrections referrals.

RCF's are not the old county homes of yesteryear. We receive clients from throughout the state of Iowa. Most admissions are directly from psychiatric hospital and are certified as needing 24 hour care and supervision. Psychiatric hospitals are discharging patients at higher acuity levels. This may be occurring due to insurance payments. (Clients have been discharged to Prairie View when unstable.) Yes, the budgets have to be balanced, but at what human expense? These are "someones": a mother, son, granddaughter or great niece.

RCFs need to be included in core services available to all Iowans with disabilities. RCFs have become the safety net for many people throughout the state, when no other help was available. (Without Prairie View a lot of people would still be in MHI, because no one else would have given them a chance, after tons of admissions and long hospitalizations.) RCFs have been the only hope for some. Who is going to fill their shoes? Please plan carefully if RCFs are not included in core services. Do not abandon the variety of people served currently through RCFs who are certified by physicians as needing 24 hour care and supervision. I don't know anywhere that the quality of Prairie View's or any other RCFs treatment, nursing, activities, environmental services, business, dietary, and other services could be provided more cost effectively to clients with the level of needs we serve.

Thank you for considering my concerns. I can be reached at 563-380-6192.

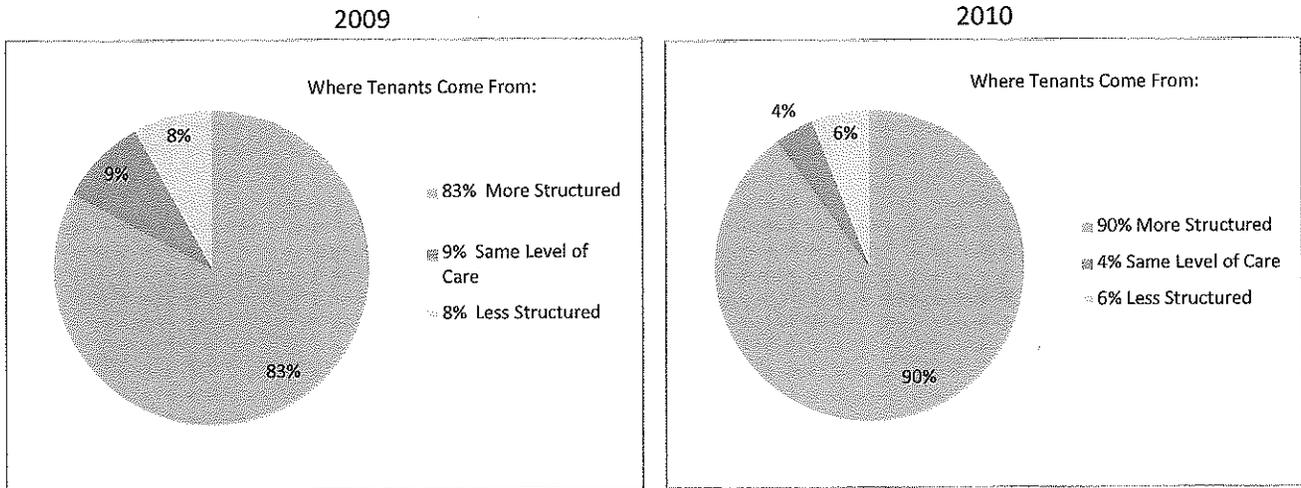


Ann Bunn, LBSW, Adm/CEO  
Prairie View Management, Inc.  
18569 Lane Road,  
Fayette, IA 52142

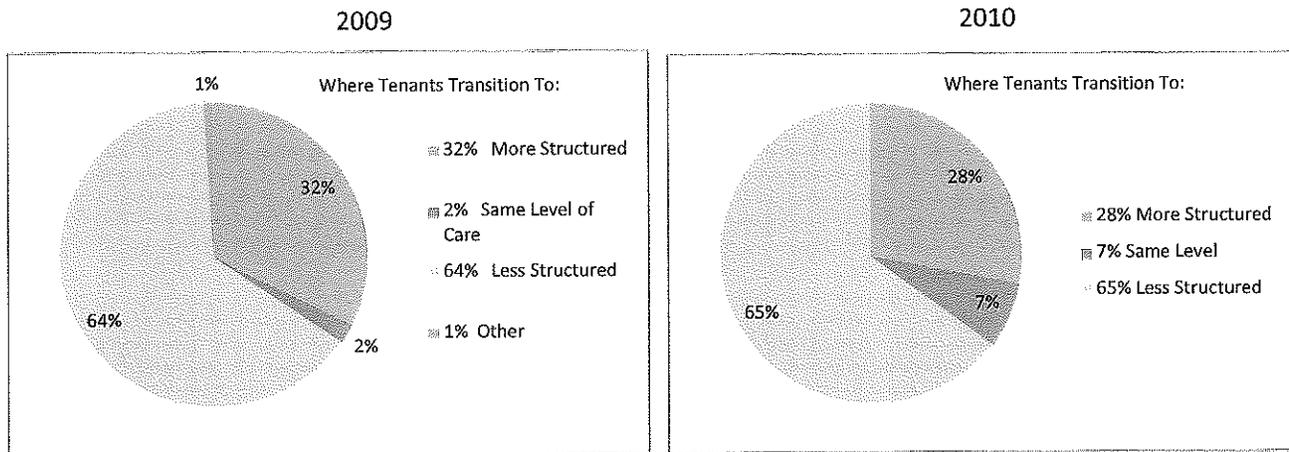
563-425-3291  
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[adm\\_pvmi@netins.net](mailto:adm_pvmi@netins.net)

# PRAIRIE VIEW MANAGEMENT, INC.

Most clients Are Admitted From More Structured (and More Expensive) Living Arrangements.



Most Clients Are Discharged to Less Structured (& Less Expensive) Living Arrangements.



2009 Admission and Discharge Information

<b>Month</b>	<b>Referrals</b>	<b>Admissions</b>	<b>Discharges</b>
<b>January</b>	22	6	6
<b>February</b>	26	9	8
<b>March</b>	12	7	4
<b>April</b>	20	7	7
<b>May</b>	18	6	7
<b>June</b>	22	6	5
<b>July</b>	35	7	5
<b>August</b>	23	5 (1 respite)	7
<b>September</b>	23	9	8
<b>October</b>	24	7	7
<b>November</b>	26	7	6
<b>December</b>	21	8	6
<b>Totals</b>			

Beginning census 82  
 March detail as of 3/31/09, Census 86  
 June detail as of 6/30/09, Census 85  
 September detail as of 8/30/09, census 86  
 December detail as of 12/31/09, census 90  
 Average daily census for 2009 was 85

General notes: Our referrals continue to remain strong, despite our limited bed availability and the fact that we have to tell our referral sources, at times, that we have “no male openings” or “no female openings” anticipated for “X” amount of time. We continue to review and assess referrals so that we remain visible to our referral sources. Our most frequent referral source for 2009 was St. Luke’s Hospital psychiatric unit in Cedar Rapids. MHI Independence was a close second. Other regular referral sources include: Mercy psychiatric unit in Cedar Rapids, the Blackhawk County CPC office, Allen Hospital Mental Health Unit, and the Iowa Department of Corrections. We continue to draw occasional referrals from throughout the State.

2010 Admission and Discharge Information

<b>Month</b>	<b>Referrals</b>	<b>Admissions</b>	<b>Discharges</b>
<b>January</b>	19	4	6
<b>February</b>	11	3	4
<b>March</b>	20	6	8
<b>April</b>	16	4	9
<b>May</b>	22	13	11
<b>June</b>	26	8	5
<b>July</b>	38	10	9
<b>August</b>	18	7	6
<b>September</b>	18	7	10
<b>October</b>	18	13	10
<b>November</b>	11	5	4
<b>December</b>			
<b>Totals</b>	217	80	82

Beginning census 89  
 March detail as of 3/31/10 Census 85  
 June detail as of 6/29/10, Census 85

St. Luke's in Cedar Rapids and Black Hawk County CPC office appear to be our strongest referral sources at present. Referrals have slowed as the word is out that we have been relatively full. We have put people on a waiting list to be assessed when we have openings.

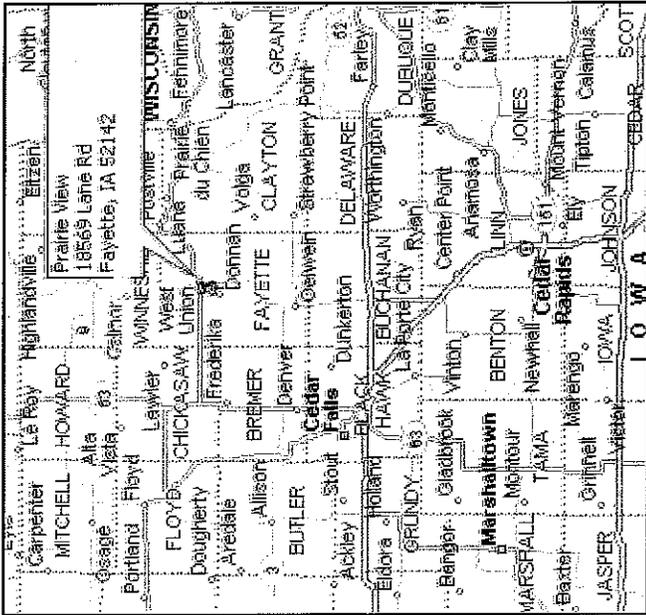


## LEISURE

## AND

### RECREATION:

- ◆ Stimulating environment encourages special interests, hobbies & talents
- ◆ Variety of activities each day
- ◆ Travel to community events
- ◆ Parties, bingo, exercising, sing-a-longs, picnics, dances, Bible study, ball games, church/mass, fishing, bowling, library, arts, gardening, crafts, current events
- ◆ Self-advocacy and leisure activities
- ◆ Large outside area to walk



Serving all areas of Iowa

Approx. 5 minutes South of West Union

Approx. 5 minutes North of Fayette

Approx. 1.5 hours North of Cedar Rapids

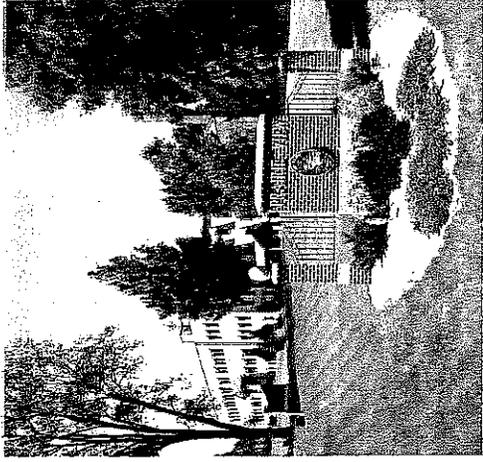
Approx. 1 hour Northeast of Waterloo

Approx. 2 hours Northwest of Dubuque

### Prairie View Mission:

To provide quality services to preserve and improve the safety, health, welfare, and comfort of its clients in the least restrictive environment and in the most cost effective manner.

## PRAIRIE VIEW MANAGEMENT, INC.



18569 Lane Road

Fayette Iowa 52142

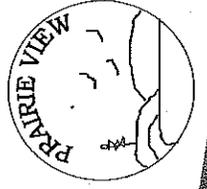
Phone: 563-425-3291

563-422-5606

Fax: 563-422-5607

Email:

[pvmi@netins.net](mailto:pvmi@netins.net)



## SERVICES

- ◆ 24-hour services and supervision for adults
- ◆ Help people maintain abilities and develop skills to reach their maximum potential
- ◆ Treatment for persons with mental health and substance abuse problems
- ◆ Skill-building Groups in the areas of:
  - Healthy Relationships
  - Coping Skills
  - Self-Esteem
  - Anger Management
  - Wellness
  - Token Task Therapy
- ◆ STEPPS: Intense emotion treatment
- ◆ Schizophrenia Support Group
- ◆ On-site Substance Abuse Treatment
- ◆ Habilitation
- ◆ MR, MI, BI Waivers  
SCL and CDAC
- ◆ Respite Care: Temporary supportive care during the day, overnight or longer
- ◆ Community Support Services
- ◆ SCL & Home-Based Habilitation
- ◆ Adult Basic Education classes
- ◆ Simulated Apartment Program
- ◆ Outpatient counseling and medical services available in the area

## HEALTH CARE :

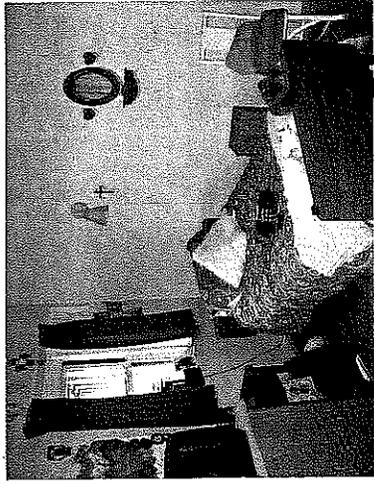
- ◆ Licensed Registered Nurses
- ◆ LPN's
- ◆ Nursing Assistants
- ◆ Certified Medication Aides
- ◆ Direct Care Providers
- ◆ On-site physician consultations
- ◆ Registered dietician plans special menus



*Caring Staff providing quality care, assistance, and supervision.*

## SOCIAL SERVICES :

- ◆ Licensed Social Workers
- ◆ Master's level counselor
- ◆ Professionally trained Group Facilitators
- ◆ Program Planners along with each client's interdisciplinary team develop individualized plans
- ◆ On-site consultation with psychiatrist
- ◆ On-site substance abuse counselor
- ◆ Primary Staff system: in house case worker



## ACCOMMODATIONS:

- ◆ Private and semi-private rooms
  - twin size bed, lounge chair, dresser, night stand, closet
- ◆ Efficiency apartments
- ◆ 3 meals and 3 snacks each day
- ◆ Canteen Room
- ◆ Breezeway where smoking is allowed
- ◆ Central air conditioning
- ◆ Satellite Television
- ◆ Basketball hoop
- ◆ Sports and exercise equipment available
- ◆ Transportation to medical appointments
- ◆ Wii Game System, movies and books
- ◆ Lounge area w/ television on separate wings



# Hope Haven

Area Development Center Corporation

1307 Broadway, West Burlington, Iowa 52655 [www.hopehavencorp.com](http://www.hopehavencorp.com)

September 16, 2011

Greetings.

My name is Bob Bartles. I'm the Executive Director of Hope Haven, a southeast Iowa nonprofit service provider based in Burlington. Our agency serves over 300 people with disabilities over a 4 county area. We're happy that the State is considering reform and is including stakeholders in the discussion about how to structure the new system.

## LOCAL CHOICE FOR COUNTY REGIONAL AFFILIATION

We're very pleased that counties will be allowed to form their own regions, without being tied to a particular urban center. Our services are provided in rural southeast Iowa. We have a mutually supportive community based network there. The providers, service recipients, their families and the County CPC's usually know each other. This results in flexible, creative and qualitative services for people with disabilities. Having the minimum size Region be 200,000 persons or even less will allow us a good shot at preserving this positive aspect of the existing service system.

## REGULATORY RELIEF

Some regulations drive up costs to the State without any measurable positive outcome for people with disabilities. Having a mechanism for periodic review of regulations would be good. Having a requirement on developing new regulations like the one below (introduced in last year's legislative session) would be good as well;

Except as otherwise explicitly authorized by state law, a state administrative agency charged with the implementation of a federal statute, regulation, or policy shall not exceed the specific requirements of that statute, regulation, or policy.

Administration  
1307 Broadway  
W. Burlington, IA 52655  
(319) 754-5774  
Fax (319) 754-0045

Vocational Services  
(319) 754-5774  
Fax (319) 752-1672

Development Office  
(319) 754-5774  
Fax (319) 237-1020

ICF/MR  
(319) 752-9838  
Fax (319) 754-0045

Residential Services  
(319) 752-8805  
Fax (319) 237-1158

Flexible Services  
PO Box 409  
Mt. Pleasant, IA 52641  
(319) 385-9980  
Fax (319) 385-9979

Cottonwood Care Facility  
910 Cottonwood, Suite 100  
Burlington, IA 52601  
(319) 237-1072  
Fax (319) 237-1075

## GUARDIANSHIP AS A CORE SERVICE

There are occasions when people with disabilities are exploited or neglected because of the lack of an appropriate guardian. A change I suggest for the system is to recognize guardianship/conservatorship as a core service worthy of State financial support. At one time, Iowa had a State Substitute Decision Maker role. Reinstating the role would be one way to address this pressing need. Helping potential new guardians with the expenses (legal and otherwise) associated with the role would be another.

## STATEWIDE UNIFORM RATE SETTING METHODOLOGY

The State really needs to use generally accepted accounting principles and have a uniform rate setting methodology for all services. The present system has retroactive cost reports, which means providers cash flow the State for 18 months. A prospective rate setting system would strengthen local community based service providers.

The present system has caps for some services and categories of costs. We need to remove these caps on rates. The caps cause some services, like desperately needed Supported Employment, to be largely unavailable for many persons with disabilities. In the last year at Hope Haven, we helped 80 people with disabilities get and retain jobs. Because of capped rates, we lost tens of thousands of dollars doing that.

Thank you for the opportunity to make comments about the system. This redesign process is a very positive development. I appreciate the efforts being made to have a much improved support system for people with disabilities.

Bob Bartles  
Executive Director  
Hope Haven

Hope Haven



Bob Bartles  
Executive Director

1307 Broadway  
West Burlington, IA 52655

319-237-1333  
Fax 319-754-0045  
bob.bartles@hopehavencorp.com



% Van Buren Job Opportunities  
Keosauqua, IA 52565

September 13, 2011

Ms. Karalyn Kuhns  
DHS, MHDS  
Chairperson, Adult ID/DD System Redesign Work Group  
Hoover Building  
1305 E Walnut Street  
Des Moines, IA 50319

Mr. Robert Bacon, Director  
University of IA  
CEDD  
Co-Chairperson, Adult ID/DD System Redesign Workgroup  
209 South Quadrangle, 225 CDD  
100 Hawkins Drive  
Iowa City, IA 52242

Dear Ms. Kuhns and Mr. Bacon:

IA-APSE is elated at the state's endeavors in redesigning our mental health and disabilities system. We applaud the efforts of your Adult Intellectual and Developmental Disability System Redesign Workgroup as you develop recommendations for the Legislature to carry out this redesign.

As a state chapter of the international association of APSE we are very interested in systems that promote employment as the first and preferred outcome for all Iowans with disabilities. APSE is a growing national non-profit membership organization, founded in 1988 as the Association for Persons in Supported Employment, now known as APSE. APSE is the *only* national organization with an *exclusive focus* on integrated employment and career advancement opportunities for individuals with disabilities. IA-APSE is one of 36 chapters in 35 states and the District of Columbia. As a state chapter, we are very interested in the efforts of your work group.

We understand that one of the responsibilities of this work group is to provide clear definitions and requirements for the array of core services and other supports to be

included in regional adult disability services plan including both Medicaid and non-Medicaid funded services. This offers a great opportunity to bring services and supports for Iowans with disabilities into alignment with national thinking and current values that should be driving our system.

As the state chapter of the national association of APSE, we beseech you to include competitive employment as a core outcome. May we suggest the following commonly used and federally supported definition of competitive employment:

- Regular or customized employment where employees with disabilities are paid by the business (unless self-employed) at minimum or prevailing wage and benefits
- Employment which affords regular and ordinary opportunities for meaningful interactions with co-workers without disabilities, and/or customers and/or the general public

For too long funds have been spent on services that have few outcomes, maintain the status quo and most unfortunately, keep individuals with disabilities in poverty and thus dependent on public dollars. Supported Employment, an employment strategy to assist individuals with disabilities to gain and maintain competitive employment, has been noted in a long history of research to support its' efficiency.

Supported Employment is a system of supports for individuals to assist them to achieve competitive employment. It provides individualized assistance such as job development, on-the-job support and on-going supports. It is based on the following principals:

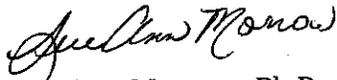
- Work is in integrated settings
- Individuals are paid at the same rate as others performing the same work
- Placement first: A job is secured and the person and then trained for that job, rather than the traditional train and place as in readiness models
- Zero rejection—everyone can work with proper supports
- The supports provided are flexible and individualized
- Support is life long
- Individuals have choices

Years of data indicate that using the supported employment strategy to assist individuals with intellectual and other developmental disabilities to obtain and maintain competitive employment rather than employment services that are based on the readiness model are more cost effective, result in more rapid placements, provide greater return on investment, and result in greater income for individuals with disabilities. Some studies suggest that supported employees are 64.5% more cost-effective than sheltered workers. In Iowa we know that approximately 34 million dollars are spent in facilities-based employment services while only 9 million

is spent in community-based employment services. Likewise, we know that it is human nature to "follow the money", thus the inequity of segregated services over integrated ones while denying thousands of Iowans with disabilities the services and supports that could positively impact their life. Additionally, a national study looking at costs of providing supported employment services for individuals with intellectual disabilities served by Vocational Rehabilitation agencies from 2002-2007 found that the benefit-cost ratio for Iowa taxpayers was \$1.62. That is, for every \$1.00 spent on supported employment \$1.62 was returned in the form of taxes paid and reduced governmental subsidies. It makes sense that Supported Employment be a core service to assist individuals to achieve competitive employment. In this time of fiscal austerity it is imperative that the limited dollars be spent on services and supports that truly benefit Iowans with intellectual and developmental disabilities.

We recognize the difficult task set before you. We applaud your efforts. We thank you for your work and celebrate this redesign effort as an opportunity to move Iowa forward with best practice in employment-related services. If we can be of any service in your efforts, please do not hesitate to contact us.

Sincerely,



SueAnn Morrow, Ph.D  
President  
319-931-5781

Do you have questions or comments we  
can share with workgroup members

I work at our drop-in center  
in Fort Dodge. Our center is open  
18 hours per day, seven days a week.  
A few years ago our hospital closed their  
psychiatric unit partly due to the efforts  
of our drop-in center. Should there

be a downward adjustment in hours  
of service or opportunity of service  
we will have 60-70 people per day  
with no place to go except isolation  
in their homes or return to hospitalization. 1

November 7, 2011

Honorable Interim Committee Members:

The redesign of the Mental Health and Developmental disability system is a daunting task and I thank each of you for your efforts to take on this responsibility. As you go through the arduous task of constructing a new method of care, under a very tight time frame, I have compiled my thoughts on what I perceive to be the trajectory of the redesign at present and respectfully request you evaluate my points below. It is my hope that in succinctly outlining "Known Truths" with the corresponding responses of "What to Do" you may give thought to the development of the system with clarity and purpose so that the end result will be a highly effective and efficient process for doing business based on a sound basis of common sense and practicality. My thoughts are as follows:

### **Known Truths**

1. State cost will not be contained by adding another layer of management.
2. State cost will not be contained by eliminating personnel, knowledge base, and infrastructure of a system that is paid for by a lower level of government
3. Cost will not be contained by expanding on the base of populations served without a reduction in service.
4. Cost will not be contained by expanding on the number and amount of services provided.
5. Transactional friction will not be reduced by displacing transactional friction amongst local government. There is cost wherever it is located.
6. Better service will not be provided the farther away or less accessible it is from the customer.
7. Integration of disabled individuals cannot be fostered by simply moving them into a home with a lesser number of inhabitants that happens to

be in a community which may or may not be equipped to offer specialized supports to meet their needs.

8. Job creation in the highly competitive open market cannot be done without educating and training competitive individuals to fill the position.
9. New or diversified professional services cannot be created without addressing the barriers to creating and diversifying services head on.
10. It is not advisable to terminate a highly intricate system without having developed a sufficient replacement that addresses clearly described desired outcomes.

### **What To Do**

1. Delineate roles and responsibilities of the state and county- these are the only two entities at present with the capacity to levy funds.
2. Allow each level of government to moderate accordingly their personnel, knowledge base, and infrastructure of the system via clearly defining roles and responsibilities.
3. Perform a population and service cost analysis of persons to be served per state plan and ADA standards.
4. Identify core services (Medicaid and non Medicaid services that are complimentary to each other) based on population and cost analysis findings with the principles of Olmstead being the guiding philosophy.
5. Reduce transactional friction through proprietorship of system function. Assign function to county and state based on goals and desired outcomes for the two levels of government and their respective charge.
6. Foster local access and local provision of service.
7. Incentivize true integration which has more to do with personal and societal incorporation than it does with residency and household.
8. Build on individual strengths and motivations to promote optimal level of functioning that has employer value.
9. Identify barriers to professional services and find ways to overcome those barriers which incentivizes professional service development and retention.

10. Clearly define the goals and objectives for making system changes and create tangible and measurable action steps to achieve outcomes.

In closing, I again thank you for your efforts and your time and attention to the information that I have provided along with all other correspondences you have undoubtedly received from your constituents.

Respectfully,

Ryanne Wood