

THE VOICE

Volume 2, Issue 4

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The Unseen Consequences of Cuts to PCA Services

by Tom Johnson

The eligibility rules for Personal Care Attendant (PCA) services changed substantially in 2010. The new rules disproportionately limit the eligibility of persons with a mental illness. The cuts in PCA services come with serious consequences for people like Henry.

Henry lives with schizophrenia. He functions well within the community as a result of his conscientious adherence to the advice of his doctor and therapist. In addition to these important supports, Henry received PCA services, which were very important to his health and well-being.

Henry's symptoms of mental illness are well controlled, but there are areas of his life where Henry needs support. Henry has an excellent appetite, and he enjoys almost any food. Unfortunately, not all foods are equally healthy, and Henry benefits by having a PCA point out food selections that do not increase his significant risk of diabetes or put him at risk to further elevate his blood pressure and cholesterol. With a recommendation from his PCA, Henry is happy to select a variety of foods, including fruits and vegetables. Without assistance and recommendations, Henry fills up on high fat, processed foods. Over the three years in which Henry received PCA services, his blood sugar, cholesterol, and blood pressure dropped. His doctors were very impressed with his efforts.

Besides the benefits to diet, Henry often gets assistance from his PCA in filling out forms and scheduling appointments. The PCA often gives Henry a ride to the clinic when a bus can't get him there. Henry lives in his own apartment and is a good and quiet neighbor, however, Henry has a difficult time maintaining a clean apartment. Without PCA support in cleaning his place, Henry's continued residency could be jeopardized because his landlord or neighbors might find cause for complaint.

Unseen Consequences continued on page 7

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Celebrating Recovery

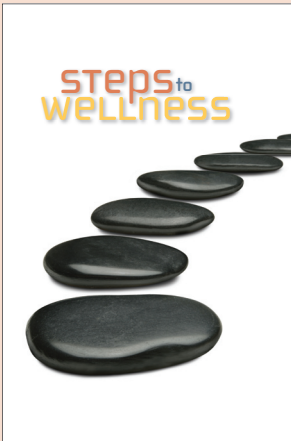
Tuesday, October 5, 2010, 9:30 a.m. - 3:00 p.m.

We invite you to attend MHAM's 2010 Education Event, *Celebrating Recovery*. This event will provide information about self-care and offer tips on becoming a partner in your own care. We will also unveil our new *Steps to Wellness* self-care kits. Lunch will be served.

- \$15 in advance
- \$20 at the door
- \$40 to exhibit at the Wellness Fair
(includes admission to the event and lunch)

Ramada Plaza Hotel
1330 Industrial Boulevard NE
Minneapolis, MN

Register online at mentalhealthmn.org
or call 612-331-6840 or 800-862-1799.



We are thrilled to announce that our new *Steps to Wellness* self-care kits will be available October 5.

This personal tool kit contains several tools designed to work together to help you develop a plan for self-care, address a crisis should it arise, and advocate for yourself to receive treatments that work best for you.

- A self-advocacy wallet card
- A medication wallet card
- A medication worksheet
- A daily wellness chart
- An individual crisis plan
- A crisis plan to share with your support system
- A wellness journal

We will unveil the kits at the *Celebrating Recovery* education event. After the event, kits will be available via our website (mentalhealthmn.org). They can also be ordered by calling 612-331-6840 or 800-862-1799.

The *Celebrating Recovery* event and the *Steps to Wellness* kits are made possible through support from an educational grant from Lilly USA, LLC; a charitable contribution from Janssen, Division of Ortho-McNeil-Janssen Pharmaceutical, Inc.; a grant from Park Nicollet Foundation Healthy Community; and a grant from Pfizer Healthcare.

Public Policy Update: Local Advisory Councils

by Ed Eide

It's fall. We are getting into the swing of things with school starting, the State Fair ending, and fresh vegetables everywhere.

I will once again be going around the state to meet with Local Advisory Councils (LACs) and set goals for the next year. We will work hard to get more people with mental illnesses involved in decision-making related to mental health services. Empowering people to have a say in their lives is crucial to recovery and wellness. I will meet with four LACs in September, and I am looking forward to meeting new people.

The issues discussed at the LACs center around access to services, transportation, crisis services, and stigma. Many LACs have looked at providing education on mental illnesses to reduce stigma. On a statewide level there will be proposals coming on transportation services in a crisis situation.

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of Minnesota **mham**

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The MHAM newsletter is published five times per year, with a circulation of 4,500.
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Letter from the Executive Director



Whether we like it or not, we are ultimately responsible for our own health. We can choose to take care of our health, or we can let our health deteriorate. We can seek help when we are ill, or we can choose to put it off and hope for the best.

Minnesota is launching the 10 x 10 Project. The goal is to improve the life expectancy of people with mental illnesses within the next ten years. Studies show that people with mental illnesses live 25 years less than people without a mental illness on average. The primary reason for the gap is due to issues other than a person's mental illness. It is often the case of not monitoring overall health.

We all need to drive our own health care, or someone else will. We must be the primary decision maker when it comes to our health. We must monitor our weight, cholesterol, and tobacco and alcohol use in order to live longer. We must ask the right questions of our health care providers at the right time. In other words we must own our health and not let someone else do it.

Our *Steps to Wellness* kits can provide a way to own your health care. At our event on October 5th people will find handy and easy tools to begin to live a healthier life. Come join us!

On another note relating to our health, we have a bunch of elections coming up. We will elect a new governor and there are 26 legislative districts where there is not an incumbent running. We took some hits in mental health funding in the last session, but it could have been worse. This session will be dealing with a significant deficit and looking at places to cut services.

We all need to drive our own health care, or someone else will.

For some perspective, a recent national survey conducted by GuideStar revealed some concerning news. According to their report, *The Effect of the Economy on the Nonprofit Sector: A June 2010 Survey*, "those involved in mental health and crisis intervention were more likely to report a decline in contributions (51%). Unfortunately, 78% of mental health organizations also reported an increase in demand for their services, well above average." You can download the full report at <http://www2.guidestar.org/rxg/news/publications/nonprofits-and-economy-june-2010.aspx>.

You need to ask the candidates where they stand on funding mental health services. When they come to your door, ask questions and tell them you want them to support mental health services. We found that stories from real people helped keep funding for some services targeted for cuts in the last session. You can find questions and information on our website.



Make your voice heard!

Your Rights in the Workplace

by Anna Raudenbush

It seems every day the newspaper carries stories about increasing unemployment rates, dire economic forecasts, or declining job availability. With budgets shrinking and companies cutting back on employees, those who are employed count their blessings. The economic conditions right now make the prospect of unemployment especially daunting, and many employees are taking extra measures to keep their jobs—in some cases even putting up with discrimination and inappropriate behavior in the workplace.



Though people with disabilities are a protected class under the Minnesota Human Rights Act, discrimination can and does persist in workplaces across the state. I have talked with many people with mental illnesses who endured harassment, a hostile work environment, and inappropriate comments. They were uncomfortable asserting their rights for fear of losing their jobs and health insurance coverage.

Many employers are aware of the damage a discrimination case could do to their reputation and finances. While many implement diversity training and strive to create a harmonious workplace, others hold on to their prejudices. Discrimination can be subtle and difficult to prove in court. An employer may fire an employee for discriminatory reasons but claim on paper it is due to poor work performance. Both the employer and employee may be aware the termination was based on discrimination, but the employee may not have enough hard evidence to file suit.

It is understandable that people are desperate to keep their jobs. However, it is important to know what your rights are, and how to protect yourself from discrimination at work. One way to protect yourself is to refrain from disclosing information about your mental health. In some cases, an employer may need to know if you have a disability (when claiming disability benefits or requesting an accommodation), but rarely do they have the right to know specific diagnoses. Medical records are private and protected by federal privacy laws. At no time should an employer ask personal questions about your mental health.

For example, a question like: “Do you see a therapist?” or “Have you ever had depression?” from an employer would be inappropriate. An appropriate response might be, “That is not something I feel comfortable discussing at work.” It may also be appropriate to file a complaint with their supervisor or the human resources department. You should never feel pressure to share your private medical information with your employer.

For more information on protecting yourself at work, contact a MHAM advocate at 612-331-6840 or 800-862-1799. We are available from Monday to Friday from 9 a.m. to 4:30 p.m.

What's In A Name?

by Benjamin Ashley-Wurtmann

We recently saw an interesting article from Dr. Hyde, the administrator of the Substance Abuse and Mental Health Services Administration (SAMHSA). She wrote about the various terms that people use when talking about mental health issues and chemical dependency. You can find the links to the article on our blog at mentalhealthmn.org.

The questions she raised were important. Is a person who uses mental health services a patient? A consumer? A survivor? Is recovery something you can define? Is it a process? Or should we be talking about wellness instead?

We may all be talking about similar ideas, but the words we use can reflect some basic choices and priorities we've made. Language can describe people as active and at the center of things, or it can talk about them as objects that are acted on by others. It can make people feel powerful or powerless.

One of the problems is that old stigmas often find ways of attaching themselves to new language. What was once liberating and new can become weighed down with time. People who wanted to emphasize the decision-making power and centrality of the person who was seeking

treatment first used the term "consumer." While it still remains a widely used term by many people, we are hearing that it is troubling for some who feel it has negative connotations of a person who is not contributing to society. We have heard "recipient" or "person receiving services" as possible alternatives.

One of our preferred terms is "people with mental illnesses." We think it's important to use people-first language that emphasizes that we are talking about individuals who have different experiences and may be affected by their illnesses in a variety of ways. We know that there is more than one mental illness, and people may have more than one diagnosis, or their diagnosis may change over time, so we pluralize "illnesses."

In light of recent tragic news stories, we've heard the phrase "the mentally ill" in a way that lumps many people together and defines them negatively. We know that there is a broad spectrum of mental health and illnesses and that most people move along that spectrum over time. There's no one experience of having mental illnesses: one size definitely does not fit all.

There is no set of terms that would be completely acceptable to everyone. We think it's vitally important to listen. Even if a term isn't the language we would usually use, we want to respect the right of people to name their own experiences. In return, we hope that everyone approaches the conversation in good faith. If the language someone has used seems troubling or offensive, ask questions and find out if it can be an opportunity to be honest about the impact of our words. There's a lot to talk about: promoting wellness, ending stigma, and showing our concern for others. When language differences stop the conversation, we all lose out.

We look forward to hearing more input from all of you. Join the conversation on our blog or by sending us a line at info@mentalhealthmn.org.



National Institute of Mental Health (NIMH) Research Project Focuses on Coordinated and Aggressive Treatment for Early Phase Schizophrenia

Recovery After an Initial Schizophrenia Episode (RAISE) is a NIMH research project that seeks to fundamentally change the trajectory and prognosis of schizophrenia through coordinated and aggressive treatment in the earliest stages of illness. RAISE is designed to reduce the likelihood of long-term disability that people with schizophrenia often experience. It aims to help people with the disorder lead productive, independent lives. At the same time, it aims to reduce the financial impact on the public systems often tapped to pay for the care of people with schizophrenia.

NIMH has awarded separate contracts to two independent research teams to develop interventions that can be tested in real-world treatment settings and be readily adopted and quickly put into practice should they prove successful. The contract awards, bolstered by funds from the American Recovery and Reinvestment Act of 2009, have been awarded to the Feinstein Institute for Medical Research (Principal Investigator, John M. Kane, M.D.) in Manhasset, NY, and to the Research Foundation for Mental Hygiene at Columbia University (Principal Investigator, Jeffrey A. Lieberman, M.D.) in New York City.

The team led by Dr. Kane has developed the RAISE Early Treatment Program, a research study that will be conducted in community clinics across the United States. The team led by Dr. Lieberman has developed the RAISE Connection Program, a research study that will be conducted at community clinics in partnership with the Maryland and New York state mental health systems.

Treatment models being tested in both the RAISE Early Treatment Program and the RAISE Connection Program studies focus on intervening as soon as possible after the first episode of schizophrenia. Each model integrates medication, psychosocial therapies, family involvement, rehabilitation services, and supported employment, all aimed at promoting symptom reduction and improving life functioning.

While the studies have similar goals and will be conducted in diverse, real-world health care settings, they differ in research methodology, the nature and location of clinical sites, the organization of intervention teams, specific services being offered, and how services will be reimbursed or paid for. Taken together, the results of these complementary studies will inform the most effective strategies for improving the recovery of functioning and quality of life for people affected with schizophrenia.

Excerpted from the NIMH website. For more information on the RAISE project and other research and information pertaining to schizophrenia, please visit <http://www.nimh.nih.gov/health/topics/schizophrenia/index.shtml>

Public Policy Update continued from page 2

Over the summer we shared information on how the GAMC program changed. Many counties around the state transferred people from GAMC to Minnesota Care. This process was a temporary shift to make sure people had adequate health care. The counties acted quickly in order to meet the needs of their residents, and we commend them for that. We need more of this type of innovative thinking.

But what happens after the upcoming election? Will we opt in for early MA in order to provide health care to our poorest residents? This would be the most cost effective method to provide appropriate health service. These and other health related issues might be the central issues before the new governor and legislature.

We will look to LACs to help us maintain needed services to people with mental illnesses. If you serve on an LAC and want more information please feel free to contact me at edeide@mentalhealthmn.org or 612-843-4868, ext. 1.

2010 Memorial and Honor Gifts to MHAM

In Memory

David Birch
Angel Birch

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Douglas and Jane Fiola

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Clare and Jerome Ritter
Sandra Williams

Laurie Kramer
Janice Gepner and Eric Newman

Kim Lutes
Dianne Lutes

Timothy Norling
Jerry and Carol Norling

Janet O'Neill
Frank and Janet O'Neill
Margaret O'Neill Escabi and José Escabi

Yin Simpson
Robert and Pearl Bergad

CORRECTION: In the last edition of *The Voice*, we incorrectly listed Cheryl A. Renk's 2009 gift in honor of her mother, Kathy Renk. The gift was in honor of Kathy and not a memorial. We deeply regret the error and apologize for any confusion.

This list is current as of August 31. Every effort has been made to ensure accuracy. If you note an error or omission, please accept our apologies. You can notify us of changes by calling Nancy Paul at 612-843-4868, ext. 9.

Unseen Consequences continued from page 1

As was the case with hundreds of people with mental illnesses in 2010, Henry lost his eligibility for PCA services. Henry contacted MHAM and spoke with an advocate. The advocate suggested that it was worth the effort to appeal the decision to terminate PCA services, although the chances of success with the new eligibility criteria made it unlikely that the appeal would result in reinstatement of services. The appeal was not successful, so the advocate guided Henry toward similar services through the Adult Rehabilitative Mental Health Services (ARMHS) Program. Henry was eligible for ARMHS, and he is receiving the services. The program will most likely meet Henry's needs, but there are some issues which may still arise.

Trust is an important element of a mental health service relationship, and change is difficult for many people. As people are shifted away from PCA services and into other supports, it will take time for individuals to build trust and confidence. In the meantime, some of their needs may not be addressed. Moreover, the ARMHS program is more costly than the PCA program, so the new services for Henry and people like him will not result in a savings to the state.

Support Groups

DULUTH SUPPORT GROUP FOR PEOPLE WITH MENTAL ILLNESSES

1st and 3rd Thursday of each month, 5 – 7 pm, Miller Dwan Medical Center, Meeting Room 1 – 3, Lobby Level, East Side, *For more information, call MHAM at 1-800-862-1799.*

REACH FAMILY SUPPORT GROUPS (ALL IN GREATER MINNESOTA)

Albert Lea	4th Thursday, 7 pm	Nancy Heidal	507-373-8090
Alexandria	1st Monday, 7 pm	Linda Fahlin	320-763-3466
Bemidji	3rd Tuesday, 7 pm	Robin Wold	218-444-6748
Milaca	1st Tuesday, 6:30 pm	Mary Fehring	320-983-6724
St. Cloud	1st Tuesday, 6 pm	Dale Anderson	320-240-3327



DBSA SUPPORT GROUPS

For people living with depression or bipolar disorder and their family members and friends

TWIN CITIES

Dakota County/Eagan <i>(formerly Apple Valley)</i>	1st and 3rd Tuesday, 7pm	Audrey Weiner	651-454-8329
Eden Prairie	1st, 3rd, and 5th Monday, 7pm	Jonathan Moerschall	612-210-1704
Maple Grove	1st and 3rd Thursday, 7-9 pm	Beth Bell	612-722-4185
Mounds View	2nd and 4th Tuesday, 7 pm	Steve	763-425-6505, ext. 515
St. Louis Park	2nd and 4th Thursday, 7 pm	Pam Karls	612-867-6863
St. Paul	1st, 3rd and 5th Wednesday, 7 pm	Bobby Nemer	952-938-8941
Woodbury	2nd and 4th Wednesday, 7 pm	Marjorie Sigel	651-698-0767
		Carol Treague	651-735-2345

GREATER MINNESOTA

Albany	Every Monday, 6:30pm		320-845-6104
Crosby	Every Thursday	John Pappas	218-546-6520
Rochester	1st and 3rd Monday, 5:30 pm	Sandy (daytime)	507-282-8372
	2nd, 4th and 5th Monday, 7 pm	Jonathan (evenings)	507-292-9679
St. Cloud	Every Thursday, 6 pm	Lynn Keller	320-240-3324
Walker	Every Friday, 7 pm	Beverly Brown	218-547-3905