



Connections

— for communities that care

I WILL NO LONGER REMAIN SILENT

Brian Calley, Representative, Michigan House of Representatives

When I read the following article, which appeared in the "Weekender" edition of the Ionia Sentinel-Standard on Father's Day, June 20th, I was profoundly moved by Brian Calley's compassion and candor. What was especially heartening was that this was the voice of a State Representative. In a day when it is popular to assume a negative posture and criticize anyone in politics, here was a refreshingly, positive example of what we all want when we step into the voting booth! We desire statesmen who openly and honestly carve out a path that addresses the issues we face, regardless of how challenging they may be. (Some time after this article was written, Brian was selected to be a candidate for Lt. Governor in this fall's election.) – Clint Galloway, Editor

In the House of Representatives, I sit on the Health Policy Committee. We have taken up some pretty heavy issues in the past few years, but there is one day I will never forget.

In June of 2009, there was a young boy that sat at the committee desk testifying next to his mother. He read from a paper about what his life was like before he received help. The subject was insurance coverage for autism treatment.

His testimony detailed the characteristics and aspects of daily life with autism. He talked about how access to treatment helped him to develop and function. The fact that he was there, able to sit still and to speak to the committee, was a powerful display of the potential autistic people have.

It was an emotional day for me, and I am not an emotional person. For some reason, I could not stop tears from rolling down my cheeks as I listened to him describe himself just a few years earlier. He was a great success story, but most are not so fortunate.

As soon as it was over, I exited the room and tried to gather myself. The testimony was moving, but for me, it was personal. That boy's testimony described my daughter, Reagan.

I had concerns about Reagan before this day, but I never considered that it could be a permanent condition like autism. After all, she was only two and a half at the time.

She had stopped looking people in the eye. Her speech was limited to copying things she heard on TV. She was inflexible. She often became hysterical in public settings. She hardly slept compared to

most kids. Even the smallest change in her daily routine lead to high drama. Nothing was normal. Everything was difficult with her. Real communication was nonexistent.

I lived in denial for a while after that. I didn't even mention it to my wife, Julie. I just kept telling myself that she would grow out of this behavior. It was as if it was not really happening if there was no diagnosis. But deep down, I knew.

As Reagan grew, so did the problems. Out of desperation, I finally shared my concerns and suspicions with Julie. Together, we sought the diagnosis we so feared. By March of this year, we officially had an autistic daughter.

It is easy to retreat into hiding with an autistic child. A simple trip to the supermarket brings strong smells, loud noises, bright lights, unpredictable surroundings, and strangers – all things that are hard on an autistic person.

It is easier sometimes to just stay at home, rather than to feel the weight of people staring and wondering why you don't discipline your child who simply looks like a spoiled brat.

Autism is an epidemic affecting 1 in 110 children today. And it is increasing at a rate of 10 -17% per year. It is a frustrating condition because there is no known cause of this increase – just theories. And the network of treatment providers is totally overwhelmed.

As we try to navigate the maze of different, and often conflicting treatment options, it is necessary to celebrate small things. The kind of things that I took for granted with my other children.

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Reagan is calmed by the feel of sand. No matter what time of year it is, any time she sees sand, her shoes come off.

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Today, a year after that committee meeting, Reagan will look me in the eye. And she has the most beautiful brown eyes I have ever seen. I can't even describe what it was like when she gave me a kiss recently, for the first time.

Raising an autistic daughter takes more patience than I thought I had (the legislative process was good practice, I guess). But everything changed when I considered this experience from her perspective. It may sound silly, but I had to figure that autism was happening to her, not me.

We learn more everyday about how to be parents to Reagan. There is a lot of trial and error. And while I naturally asked God "why?" in the beginning, I now have embraced her for the treasure she is. Reagan is not defective, and I do not wish to change who she is. I just want to teach her how to cope with the ever changing world she lives in.

Get ready world. Reagan and a whole bunch of other autistic people are here and they will not be hidden away. After all, they are made in God's own image, too.

And now for "The Rest of the Story"...

A few weeks after Rep. Calley wrote the above article, he was invited to participate in a Candidate's Forum at the Ionia County Community Mental Health Authority. All the candidates were asked to address what they would do for community mental health. Rep. Calley stunned the board members and attendees with his candor by openly stating, "I will no longer remain silent." Following, in his own words, is a summary of Rep. Calley's remarks.

"I have personally attended forums at the Ionia County CMH as a candidate many times through the years. This year was different. As I sat in the audience awaiting my turn, I saw many faces that I recognized. People I had sat across the table from as the parent of a client. Several that had been in my own home, helping to develop a plan for my daughter.

Since I went last in the order of speakers, I had the benefit of hearing others speak to the question of what they would do for Community Mental Health. I heard answers that sounded a lot like the things I used to say. Answers that I realize now do not reach the heart of the matter.

My chief responsibility is to my daughter, Reagan. I am her advocate. Today, I am her voice. But quietly seeking services for her is not enough. Reagan has potential. And I have no idea at this point what that potential is. It becomes clear, however, that she will never reach that potential if she is shut away from the world.

So what can I do for Community Mental Health? I can stand up and be counted – be counted among the millions of families struggling through mental health issues. I can speak for those who cannot speak for themselves. And as a public figure in my community, hopefully, I can inspire others to do the same. Because at the end of the day, I want my daughter to grow up in a world that will embrace her the same way that I have."

Connections wishes to thank Cindy Conrad, publisher, for granting us permission to use this story which first appeared in the Ionia Sentinel-Standard. The Sentinel-Standard was the recipient of the 2003 Jim Neubacher Media Award which recognizes public media that have portrayed mental health services accurately and positively in an effort to reduce stigma of mental illness or developmental disabilities in the community. We are also indebted to Lori Kilchermann, editor, for providing copy and photographs. ■

A Growing Chorus of Voices

With this issue, marking the end of our third year, we hear voices that represent two constituencies which are vitally important to our success. The feature article is the voice of a State Representative; the other voice to which I refer is that of John Walker who speaks as a leader within the National Alliance on Mental Illness (NAMI). When individuals within our legislative chambers and those who participate in advocacy organizations recognize and gather around common issues, our voice grows exponentially. Conversely, when we spend our energy on differentiating in an effort of self-preservation, our fractured voice is muted. Finding common ground is not that difficult, as these two articles demonstrate, when we focus on what is really important. As Rep. Calley said, "My chief responsibility is to my daughter, Reagan. I am her advocate." That sense of purpose is identical to the one voiced by John Walker, who is president of Kent County NAMI. John became involved out of a deep desire to help his daughter, Debby. It could be argued that these are two very diverse constituencies but when they come together on a common issue they can move mountains.

We have all become keenly aware that we are facing critical challenges that demand changes. We are at a crossroads where we must choose between conflicting values. History is replete with stories of how severe threats have been the catalyst for bringing people together, but it can also tear us asunder. If we are preoccupied by issues of power and control, we will become hopelessly splintered. The only appropriate "self-interest" at the table is that of those we serve. It is the time to ask, "What is our chief responsibility?" If we are to truly transform our system, let the changes be driven, like Brian and John, by a vision that is focused on those we serve and support. Let us hammer out new forms that are shaped by the principles of "recovery". It will be extremely difficult to make the right changes in these challenging times without a steady eye on this mission. I am confident that as the voice of the consumer guides our decision making, we will come together. Bringing people together is what **Connections** is all about!

If you're asking, "What can I do to help?" perhaps the most powerful thing is right at your fingertips! Simply personalize this issue of *Connections* by taking the time to add a few words of your own and then forward an electronic copy* to as many people as possible: consumers, families, staff, sister organizations, county commissioners, state and federal elected officials, friends; share the voices of those who have taken the time to write their stories. Let's invite others to join the choir.

Your editor,

Clint Galloway

* A link to downloadable copies of *Connections* can be found at: www.macmh.org under "For Board Members" (middle column).

MICHIGAN'S RECOVERY COUNCIL: *LEADING THE TRANSFORMATION*

Gregory Paffhouse, CEO, Northern Lakes CMH Authority and MACMHB delegate to the Recovery Council

In the last issue of Connections we reviewed the leadership role the Department of Community Health played in the System Transformation grant which envisioned the establishment of a "Recovery Council" that is driven by primary consumers. Of course we now know the grant was funded and the first Recovery Council meeting took place in December 2005. The Council has been co-chaired by Irene Kazieczko and Phil Royster and has created:

A Vision: *Each person who receives public mental health services is supported in their individual recovery journey.*

A Mission: *To lead the transformation of the public mental health system to one based on a recovery foundation.*

The Council is currently composed of approximately 50 members appointed by MDCH, and 30 Recovery Partners (open to all interested). Meetings are every other month at Lansing Community College West. The remaining 2010 meeting is Friday, November 19.

Michigan is the only state to use the Centers for Medicare and Medicaid funding to establish a primary consumer council. As stated by Daniel B. Fischer, M.D., Ph.D., and Judi Chamberlin, National Empowerment Center, Inc., this consumer leadership is essential:

"It is widely recognized that changing the mental health system to be more responsive to consumer needs requires the participation of consumers at all levels of policy planning and program development, implementation, and evaluation. Meaningful involvement of consumers in the mental health system can ensure they lead a self-determined life in the community, rather than remaining dependent on the mental health system for a lifetime." ("Consumer-Direct Transformation to a Recovery Based Mental Health System," March 2004.)

This leadership is further supported in The New Freedom Commission report recommending that the system "involve consumers and families fully in orienting the mental health system toward recovery... Local, state, and federal authorities must encourage consumers and families to participate in planning and evaluating treatment and support services. The direct participation of consumers and families in developing a range of community-based, recovery-oriented treatment and support services is a priority." (Commission Report, p. 37).

Council members represent all geographic areas of Michigan and include representations from a wide variety of groups and organizations. These include:

Peer Specialists United
Drop-In Centers
Depression Bipolar Support Alliance
Michigan Recovery Center of Excellence
Improving Practices Leadership Teams
Clinical Directors
MI Disability Rights
Schizophrenics Anonymous
Co-occurring Disorders
Justice in Mental Health

Inter-Tribal Council
Peer Led Health and Wellness
Recovery Coordination
Consumer Site Reviewers
Youth Eliminating Stigma
MDCH
Club House
Community Mental Health
Prepaid Inpatient Health Plans

ACT Teams
Community Health Organization
NAMI of Michigan
WRAP Trainers
State Advisory Council on Aging
Office of Services to the Aging
Consumer Board Members
MI Assoc. of CMH Boards
Centers for Independent Living

Now in its fifth year, the Council remains vitally important and members remain very passionate about our leadership role. Friendships have developed, a strong cohesive group with diverse ideas has been developed, differences of opinions have been worked through, and a determination remains to our collective responsibilities. Members and partners have expressed being reenergized, having renewed hope: being inspired and excited, and believing change is really possible. Network connections have been made, stronger advocacy voices created, accomplishments made which before were only dreams, and we all have worked to become "hope givers."

There is pride in our accomplishments, including:

- Raised awareness of, legitimization, and increased passion for the Recovery Transformation Movement across Michigan.
- Provided policy input to MDCH, including the focus on health and wellness.
- Established the Michigan Recovery Center for Excellence (www.mirecovery.org).

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A *Personal* RECOVERY JOURNEY

Phil Royster, MSW

First co-chair of the Recovery Council, 2005-2010



My mother died when I was two years old. I didn't meet my father until I was in my second year at the University of Michigan. My mother's parents raised me. They were both physically abusive and mentally cruel. I was able to keep myself focused because of my love of the Lord.

I knew at an early age that education was the key to my success in life. I always did well at school. It was God's love and grace that prepared me to be the man that I am today. I've had my ups and downs like most people. I have been homeless and lived in my car for one summer.

I have a strong commitment to helping others; this is why I chose social work as a profession. I received my Masters Degree in Social Work in 1990. I have worked in all my jobs with the dedication of helping and giving good examples of how to move through life's difficulties. This can be a tough business because people have to be ready for change. Change isn't easy. To face one's difficulties in the mirror can be humbling and frightening. The one lesson I learned early in life is that you must first get on the road to success. Being on that road, you will meet people who will be willing to help you and support your efforts to do right. I was told that my mother said, "If they can do it, so can you." It does not matter if you have to take the long road around. Keep the faith and be willing to fight to make your dreams come true. God will not forsake you and he will always come when you need him the most. The longest journey begins with the very first step. I would like to encourage all to follow their dreams. It doesn't matter if others don't understand or believe in you. You must first believe in yourself and dedicate yourself to your dream. Remember, it is your dream, not the dream of others that you are pursuing. The dream is your choice. You must do the work to achieve it. Remain optimistic about yourself. There is no good thing that you cannot do as long as you remain sober.

I feel that remission of the symptoms of mental illness deserves the same recognition that cancer patients receive when their illness goes into remission. I have had the experience of being a patient and a therapist. I have reviewed other models of recovery, but I found them missing key components in the actual journey of mental illness that the patient experiences. I have attempted to take the stages in the book *On Death and Dying* by Elisabeth Kubler-Ross to show the struggle of patients as they move to remission of psychotic symptoms. Not all patients recover or have their symptoms go into remission. I hope that my experience will broaden the discussion of recovery and challenge the helping professionals to move in other directions that may be out of their comfort zone. It is my hope that treatment will embrace the hope and spirituality of the patient. These are key factors in helping the patient recover and gather the strength on the recovery journey.

Borrowing and adapting from Kubler-Ross, here are five psychological steps to recovery that seem important to me.

DENIAL: Denial is the cornerstone issue that is present when the onset of mental illness happens. What is at stake? Losing one's iden-

tity and facing society's stigma. These factors together create an almost impossible problem at the onset of mental illness.

ANGER: Although anger is considered to be the second step in recovery, it is very much intertwined in the first step of denial. Some experience – with mental illness – the loss of their identity, and the inability to relate to life's everyday demands. Anger is a common reaction for people at this stage. The illness sets us up for second guessing of everyone, including helping professionals. Facing the loss of one's identity is so painful that the elevation of self above others can become a coping mechanism. In some cases, the air of superiority is accompanied by intense anger.

DEPRESSION: Depression sets in when all attempts to create an artificial superiority have failed. If denial is still active, there will be no resolution of the crisis. Only by accepting what has happened will the patient begin to understand the elements of mental illness. With depression comes a sense of hopelessness and the mounting presence of being unfit, according to societal standards. Depression can be evidenced by a number of psychiatric hospitalizations, suicide attempts, and other destructive behaviors.

BARGAINING & ACCEPTANCE: The lucky patients are those in which medication takes away the symptoms such as auditory hallucinations and insomnia. Other patients reaching these stages have varying degrees of recovery and many have found ways to continue living successfully in spite of the presence of auditory hallucinations and varying degrees of insomnia. Some have returned to college and work; others have learned to deal with life's normal demands the best they can. At this stage, there are some absolute do's and don'ts. Some patients have learned that taking their medication is the lifeline to staying in recovery and keeping their psychotic symptoms in remission. Some have learned that drugs and alcohol cannot be mixed with their medications. It is the conscious attempt to take charge of one's recovery and remain in remission that is the foundation for those who have reached this stage.

HOPE & SPIRITUALITY: "Faith is the assurance of things hoped for; the conviction of things not seen" – Hebrews 11:1. For most health care professionals, faith and hope are difficult if not impossible subjects to approach in a therapeutic setting. A big opportunity to connect with the patient and his/her spiritual arena is being missed.

Without dreams there are no tomorrows – nor can we bear the burdens of today. Hope is a critical element in the recovery journey. For patients, it is the hope of a better tomorrow that keeps us on the road to recovery. Hope is the lightning bolt that energizes the soul to keep moving forward toward our dreams. Hope is that candle at the end of the tunnel that lights the road of recovery and propels us forward to our dreams. Hope is knowing that you are never alone because your faith sustains you day by day. Many patients are loners. By having a spiritual anchor in place, faith can provide comfort and assurance that you are on the right track. Faith is knowing that there will be people on the road who are willing to lend a helping hand. Hope is a fire that feeds itself as we gather momentum to continue. Hope is the linchpin between dreams and reality. ■

MEET MAUREEN!

Tory Hudson, Director of Program Development,
Turning Leaf Residential Rehabilitation Services



Maureen is a 50 year old woman who resides in the Supported Independent Living Program (SIP) at Turning Leaf Residential Rehabilitation and will very soon be living independently in the community with very few supports. Her journey to independence has been long, but she feels that she has learned a lot along the way and is ready to be independent. Living with schizoaffective disorder hasn't been easy for Maureen,

but with a positive attitude, support from her family, community, and the professionals at Turning Leaf, she has become a beautiful example of how a person can find a path to independence.

Maureen grew up in the northern Michigan town of Grayling. When she graduated from high school, she went to Michigan State University to study journalism. While there, she discovered that she didn't want to be a journalist, but enjoyed many of her other classes. After two years at Michigan State, she left and returned to Grayling. During this time, Maureen started to experience mental health disturbances and was referred to Northern Lakes Community Mental Health for services. She lived in various group homes in the Grayling area for nearly 30 years. Maureen says that when she first became a part of the community mental health system, she didn't take things very seriously. She was more interested in partying and having fun. But now, she says that she is grown up, and growing well into independence.

Over time, as Maureen gained greater independent living skills and needed less community living support, her case was transferred from Northern Lakes Community Mental Health to CEI Community Mental Health, in the Lansing area. For Maureen, this was proof that her CMH believed in her ability to be independent. She has resided at Turning Leaf Residential Rehabilitation Services in Lansing, Michigan since 2004 and has shown that she *does* take things seriously. She has demonstrated a true commitment to gaining independence skills. When asked what she thought of Turning Leaf when she first arrived she said, "I liked it. I never liked living in AFC homes or treatment facilities before, but I liked it here at Turning Leaf."

Maureen lived at Turning Leaf for five years before progressing to a Semi Independent Living Program (SIP), also on Turning Leaf's Lansing campus. During those five years, Maureen was an active participant in the Skill Building Program, a functional rehabilitation program with progressing responsibilities designed to assist residents in moving toward greater and greater independence.

In the Skill Building Program, Maureen began by being evaluated on basic skills such self care and activities of daily living. Once her proficiency in those areas was determined, she moved on to work-

ing on social skills and interpersonal relationships. Maureen is very fortunate to have an actively involved family support system, her mother and siblings, whom she visits regularly.

The next step in her journey to independence focused on Maureen learning home care skills such as following recipes, household upkeep, and budgeting. Eventually, Maureen graduated to the Community Skills Cottage at Turning Leaf. She knew that once she made it to Community Skills, she was just a step away from independence. In the Community Skills Cottage, Maureen learned how to access public transportation, community supports, and meal planning. Some of her favorite things to cook are Chinese sweet and sour chicken over rice and healthy snacks such as chef's salads. She was quite proud to say that she had learned to make her own salad dressing.

Once Maureen was discharged from Turning Leaf's residential program and admitted to the SIP program, she was able to "practice" independent living skills while still receiving support from the staff and therapists at Turning Leaf. In the SIP program, Maureen is working on mental health skills and vocational skills. One of the most important things Maureen has learned is that through the various levels of the Skill Building System, how all of those skills tie together to make her more successful in the independent living program. For example, Maureen knows that every month she has to plan meals and a grocery shopping list based on the amount of money that she has for the entire month. Although she does have the help of a conservator, she feels that she is putting those skills to good use. She also knows how to access community-based assistance programs in the unlikely event that she should run out of food or money before the end of the month.

Turning Leaf support staff assists Maureen with administering her medications, but also with learning about them, the reasons she takes them, and any potential side effects. She hopes to be able to administer all of her medications independently very soon. Maureen says that sometimes it is scary to think that she will need to keep taking her medications for the rest of her life, but she also says that she never wants to stop taking them, because that would lead to setbacks. She wants to remain stable and continue to become more independent.

Maureen spends her day doing a combination of independent and group therapeutic activities designed by the Skill Building program staff. In the evenings, she has the option to participate in any Turning Leaf recreational activity such as movies, bowling or other outing, or she can arrange her own independent outing or activity. She really enjoys taking walks and shopping (usually one leads to the other). Maureen is cautious with shopping because she knows she has a budget to watch. She also enjoys reading and taking bubble baths.

Maureen is able to travel independently in the Lansing area using the skills that she learned while in the Community Skills Cottage. She also uses public transportation for longer distances such as family visits to Grayling, and to visit her sisters in California and Florida. She has even traveled with her family to Rome, Italy!

Currently, Maureen is focused on getting a job. In the past she has had many jobs in restaurants – waitressing, washing dishes and bussing tables. She has even spent a summer working at the famous Grand Hotel on Mackinac Island. At times, it has been difficult for her to manage having a job and maintaining her mental health, but

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I've heard John Walker's quiet but articulate voice for nearly 20 years. When he shared with me at the 2010 Winter Conference that this would be his last conference due to term limits, I immediately seized the opportunity to ask him for an interview. John, who was President of MACMHB and recognized in 2000 with the "Hal Madden Outstanding Services" award was the first person I remember articulating some of the concerns of NAMI (National Alliance on Mental Illness). (John is presently the president of Kent County NAMI.) Since John's quiet demeanor made him almost invisible to many of our members, I wanted them to hear how the father of a daughter with severe mental illness could have a significant impact on improving the quality of life for these individuals. I also wanted to highlight the important contribution advocacy organizations bring to the table.



John, tell us a little about your background

I was trained as an automotive engineer at Michigan State University years ago, and worked in the automotive supply industry for about 30 years before being given an "early retirement," at age 55, when my employer became a new larger corporation. We were living in St. Louis, Missouri at the time.

How did you become involved in community mental health work?

Our oldest daughter, Debby, had attended the University of Wisconsin-Whitewater, and in 3½ years graduated magna cum laude. She

majored in psychology and education. She married, but after two years, was afflicted with a schizoaffective disorder. The marriage broke up, and she came to live with my wife, Betty, and me in the St. Louis area. It was a most trying time, as she was not compliant and was cycling in and out of the hospital.

We were getting on-the-job training about mental illness – a difficult time for her and us. Missouri did not have an effective CMH system at that time (1987). We learned about NAMI and found it very helpful in our time of need.

How did you end up in Michigan?

When I lost my job, I limited my job search options to either stay in St. Louis, or return to our home state, Michigan, in order to minimize the disruption for Debby. As things worked out, we wound up moving to Grand Rapids. Never having lived here before, we were influenced by our knowledge of Pine Rest, and of the Christian reputation of Grand Rapids.

I was not able to find a suitable "career-type" job. So I was essentially retired with free time.

John, your voice was one of the first I heard speaking of NAMI at MACMHB. How did you become involved in Michigan's public mental health system?

We immediately found the local NAMI here, and I was quickly drafted to be the leader. Meanwhile, a friend in NAMI who had been on the Kent County CMH Board, suggested that I apply to replace him, as he could not complete his 3-year term. I applied and was appointed to the board in 1990. So, as I tried to advocate for better services, I was being educated in the complexities of the public mental health system.

It didn't take you long to become involved at the state level.

The Deputy Director at Kent CMH, Bob Pattullo, recommended that I attend the MACMHB Policy Committee. I started there, and Floyd Smith asked me to become his co-chair. After a few years, MACMHB was desperate, and asked me to become vice president, which lead to two years as president.

Your involvement was obviously driven by your advocacy concerns, what were some of those issues?

BETTER HOUSING

The motivation of families of persons with a mental illness for housing is to enable their loved family member to have a decent, independent lifestyle. Without working, the SSI benefit they receive is about enough to pay fair market rent on a one bedroom apartment. This leaves them only with food stamps to pay for food, and nothing for clothing, utilities, transportation, or incidentals. This assumes that Medicaid pays for their medication, and medical care. At home, some of us in NAMI wanted better housing options. We were acquainted with Herb Start, President of Hope Network. He had the opportunity to take on a 911 Project that had been granted by HUD to another agency, but stalled for five years by NIMBY. ["not in my back yard"].

Herb needed a separate board of directors for the project and I accepted chairmanship. We needed to raise additional funds, as the costs had increased, but HUD would not increase their authorized funding. We raised the funds from the Department of Community Health with the help of Jim Haveman, who was director, and from the Steelcase Foundation. We completed the project, which established the Birchgrove Apartments, a complex with 19 one-bedroom apartments for persons with a mental illness, all with subsidized rent. It has been very successful. Soon after, our group of NAMI members who had formed the Birchgrove Board, learned of another interesting housing project that was floundering, so we formed a new non-profit, Good Homes, Inc., and teamed up with Habitat for Humanity to build 4 one-bedroom homes that persons with a mental illness could purchase on a 15 year mortgage that would cost much less than renting an apartment. *(continued)*

After that, we acquired two houses and opened them for women with a mental illness – with a house manager we provided. We eventually found the cash flow inadequate, so gave the Good Homes program to Hope Network.

I was also appointed to the Kent County Housing Commission Board, as it was first formed in 1998. I remained on the board for two 5-year terms and served as chairman the last few years.

BETTER CASE MANAGEMENT

Case management client ratios were much too high for the consumers to receive the help needed. ACT teams were a new thing, so we advocated for expanded ACT and improved client case loads.

John, those are very significant achievements! I also vividly recall your explanations of the problems inherent with “spend downs.” It was the first time I really understood the issue. Could you share that concern with our readers and how it has been addressed?

Spend down. What a terrible provision! Persons on SSDI (Social Security Disability Income) and Medicaid are involved. If you are able to work, you have to pay for mental health services up to a calculated amount before Medicaid can be used. Debby worked at a part-time job earning around \$400 per month. Her spend down amount was something over \$400 per month, which meant that each month she had to personally pay for the first \$400+ of her medications or treatments before she could get her Medicaid card. She was worse off than not working! Further, persons on spend down have to save all bills they pay and send them to Social Security proving that they have met their spend down before their monthly Medicaid card would be mailed to them. This process often took nearly the full month, and then the processing added further time, so the person had to try to get their meds or service providers to wait for payment until they received their Medicaid card. And all that paperwork for a person with a mental illness!

It has been a number of years since I was involved in a group seeking to reform spend down. After months of effort, involving many meetings, mostly in Lansing, we did not accomplish any change to the system. I'm not aware that it has been significantly changed since that time.

John, how is Debby doing now?

Debby has been quite stable now for several years, not working, but very active, (she has her own car). She knits, (participates in 2 knitting groups), she paints, (watercolors and colored pencil; is active with Grand Valley Artists). She has found two good friends, through a support group Betty and I run at our church. They are very involved with each other – a key issue for most everyone,



Debby and Betty Walker

and especially significant for persons with a mental illness. Living with us, she has a reasonably stress free place to live with people to talk to and share life issues.

It is really important for families to stay involved with their ill family member, and for the ill person to have someone they trust to stay connected.

How do you envision her future?

Debby's married sister in Wheaton, Illinois, and her married brother, in Concord, Massachusetts are both supportive, and would willingly help Debby get established there, but the move would be very disruptive – new treatment agency, loss of friends, etc. It is not a comfortable alternative.

We still have no comfortable answer for what happens when we can no longer care for her in our home. She would not like to have to move away from her friends and activities here.

What you seem to be saying is that we all need to be enmeshed in a compassionate network of friends.

This is so true. Persons who truly care about you, and are available to talk to about the myriads of questions we all face from day to day. Persons with whom we can engage in social activities. ■

MACMHB Fall Conference

October 18 - 19, 2010
Grand Traverse Resort

MAUREEN (from page 5)

now she feels like she's ready. She knows that she will need to continue to take her meds every day and use the skills that she has learned. As part of the Skill Building Program, Maureen had on-campus vocational experiences such as working in the garden. She has also had community-based volunteer positions. She feels that she is finally ready to have a competitive, community-based position. She would love to get a position as a cashier.

When asked what kind of advice she would give to a person living in AFC, Maureen says to follow the rules 100%. It is important to take your medications, even when you don't think you need them. She cautions people who may be hearing voices that they know aren't real to not hesitate in telling someone that they need help. "Voices don't go away on their own; they can disrupt and ruin your life. Get help before you get to the point where you are doing rude things like yelling at the voices while you are walking down the street."

Maureen is a true inspiration to consumers, family members and professionals alike. ■

Turning Leaf Residential Rehabilitation Services is a Lansing, Michigan based provider of residential programs and treatment services that has been passionately committed to supporting the growth and recovery of consumers throughout the State since 1995. For more information, please visit www.turningleafrehab.com.



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RECOVERY COUNCIL *(from page 3)*

- Selected and consulted on the implementation of the Recovery Enhancing Environment (REE) survey.
- Increased legitimacy, strength and influence of statewide Certified Peer Support Specialists
- Developed meaningful mission, vision and values statements.
- Brought back to where we work, and to those we represent, an increased understanding of recovery, which has influenced local decisions, promoted consumer voice, and strengthened partnerships.

There is a determination to honor our Vision, Mission, and Values, and the Council has established five workgroups consistent with its 2010 strategic initiatives:

Group One - Review state and national guidelines on recovery policies.

Group Two - Involve consumers in gathering data regarding recovery locally.

Group Three - Involve the Recovery Council in reviewing Application for Renewal and Recommitment data.

Group Four - Review state and local recovery policies.

Group Five - Begin work on a recovery curriculum and activities focused on anti-stigma, trauma, and whole health recovery.

Additionally, the Council has developed a steering committee to build an organizational structure to sustain the Council in 2010 and beyond.

This year Michael Head, Director of Mental Health and Substance Abuse Administration, MDCH, asked the Council to develop a Recovery Policy and Practice Guideline. The Council has enthusiastically accepted this charge and has made this a priority to accomplish this year. Once completed, this will be presented to MDCH, then released for public comment, and ultimately will become a contract attachment.

Mr. Head also presented this question to the Recovery Council: What should a community mental health system look like if it is based on recovery? This is a critical question to be answered since the literature supports that recovery can be facilitated, as well as inhibited, by particular features of care and the care system. In our next issue, we will address this question. ■