



# Connections

for communities that care



## JOURNEY TO RECOVERY

Greg Paffhouse

Those of us with a long history in the community mental health system have witnessed the shift from the institutional era, through deinstitutionalization, and now struggling to establish the era of community living. As summarized in a Power

Point presentation- developed by MDCH and shared with all directors, board chairs and executive board members of MACMHB prior to the strategic planning session of MACMHB in January—this movement continues to create changes not only in how persons are seen, but also in common beliefs and practices within the Michigan public mental health system.

While the Institutional Era was built on a custodial/medical model focused on protection and provision of basic needs, with the objective being control, safety and amelioration of symptoms, the Deinstitutionalization Era moved to a model which was professionally driven and programmatically oriented, with the highest priority being symptom reduction, illness remission, and skill development designed to improve functioning. Contrast these with the Community Living Era, which is built on a foundation of evidence based and promising practices, peer delivered, informal supports and self-determination arrangements. The Community Living Era has recovery, supports of living, illness management and relationship building as its highest priorities, with the objectives being community inclusion and participation, independence and productivity, the qualities of full citizenship.

Such changes have and continue to present both opportunities and challenges to our system. Let's look at this through the lens of recovery.

Recovery literature reveals that the current movement has been driven by consumer and family involvement in systems for over 30 years. Many consumers believed that the mental health services they received were not helpful and created system dependence, too many times negative treatment or lack of treatment exacerbated their problems. Organizations, such as the National Alliance for the Mentally Ill (NAMI) and the Federation of Families, advocating for individuals who are most impaired, have argued that too many were not being adequately served during this era of deinstitutionalization. Many persons were placed from institutions into the community but were not meaningfully integrated into the community. Too often, they were "strangers within their own community." Advocates began to challenge the beliefs that serious mental illnesses were permanent biological diseases; that recovery was unlikely; that a lifetime of maintenance on medication, group living, and skill development constituted "good" outcomes. They began to demand the right to "voice, choice and control" over their services and supports that would assist them in pursuing their hopes and dreams. They sought more than survival and a "stay-out-of the hospital" concept of life. They wanted to move from feeling hopeless to hopeful and sought a productive life of quality based on equality.

During the same time, research began to demonstrate that people can and do recover from severe mental illness; e.g., Harding et al., 1987; Karon & VandenBos, 1981; Ahem & Fisher, 2001. Such scientific evidence significantly supported

(continued on page 2)

*Inside This Issue...*

- A Mother's Perspective.....3
- A Personal Journey to Recovery.....4
- Winter Conference Highlights.....4
- Hope Givers, Hope Receivers and Hope Stealers .....5
- Ten Fundamental Components of Recovery .....6
- The Struggle for Esteem .....7

## JOURNEY TO RECOVERY *(continued from page 1)*

the advocacy efforts, challenged the myth that people cannot recover, and further promoted the recovery movement. The voices for change received support from several exceptionally important federal reports. These include:

*Mental Health: a Report of the Surgeon General* (U.S. Department of Health and Human Services, 1999) provided the scientific basis for transforming the delivery of mental health services.

*The National Council on Disability report, From Privileges to Rights* (National Council on Disability, 2000), highlighted the importance of having people who have recovered from mental illnesses play an active role in the policies and services of the system.

The July 2003 *President's New Freedom Commission on Mental Health—Achieving the Promise: Transforming Mental Health Care in America*, contained an over arching recommendation that services and treatments for persons with psychiatric disabilities must be recovery oriented and consumer driven. It issued this Vision: "A future when everyone labeled with mental illness will recover" and to do so "care must focus on increasing consumer ability to successfully cope with life's challenges...not just on managing symptoms."

To define recovery, the Substance Abuse and Mental Health Services Administration and the Interagency Committee on Disability Research, in partnership with six other Federal agencies, convened the "National Consensus Conference on Mental Health Recovery and Mental Health Systems Transformation" on December 16-17, 2004. The following consensus statement was developed and continues to guide transformation to a recovery-oriented system of care.

**Mental health recovery is a journey of healing and transformation enabling a person with a mental health problem to live a meaningful life in a community of his or her choice while striving to achieve his or her full potential.**

The ten Fundamental Components of Recovery are: Self-Direction, Individualized and Person-Centered, Empowerment, Holistic, Non-Linear, Strengths-Based, Peer Support, Respect, Responsibility, and Hope [see page 6].

The public mental health system history has not been based on these recovery principles or philosophy. Instead it has been based on the belief that people with serious mental illnesses do not recover and in fact generally deteriorate over time. This belief has been especially true for persons with the most severe mental illnesses. For many consumers, tradi-

tional services have decreased hope; they have been based on compliance, not recovery and wellness.

As William A. Anthony, executive director of the Boston University Center for Psychiatric Rehabilitation stated, "If we are serious about the vision of recovery, then the mental health system of the last century – which for the most part was a system characterized by low expectations, control, and no consumer-based vision – must disappear." It will be up to us and others who believe in the *Recovery Vision* to join together in providing leadership; without this collaborative leadership, we will fail and we will fail others who depend on us and who believe in us.

To promote recovery we must believe it is possible and should be expected. For people to recover they and the people around them must believe they can recover. This is true across the stages of recovery. Our challenge and opportunity is to transform our system. Much work has been done across the world, across the United States, and throughout Michigan to support each person's "journey of recovery" and to promote "system transformation." There is much to accomplish. In the next issue of *Connections* we will look at the role of the Recovery Council in leading the Michigan transformation. In this article our aim has been to promote your understanding of the history and principles of recovery so that "recovery" becomes part of the working vocabulary of every person that is concerned about the quality of services provided by our public mental health system. We hope we have succeeded. ■

*Editor's Note: Gregory [Greg] Paffhouse (pictured right) is the CEO of Northern Lakes CMH Authority and is a member of the Executive Board at MACMHB where he also serves as the liaison to the Michigan Recovery Council. Having become familiar with the excellent reports Greg provides of the Recovery Council activities, we decided it was time for Greg to share the promising news of how the principles of "Recovery" are transforming our system.*



To access the "National Consensus Statement on Mental Health Recovery" referenced in this article, go to: <http://mentalhealth.samhsa.gov/publications/allpubs/sma05-4129/>

# A Mother's Perspective

Judy Webb

Many of us are familiar with Judy Webb in her official capacity as Director of the Division of Quality Management & Planning, Bureau of Community Mental Health Services, Mental Health & Substance Abuse Administration, Department of Community Health.

However, like so many of those who are responsible for the administration and delivery of services within our community mental health system, we seldom see the matters of the heart that drive their work. In CONNECTIONS, we attempt to burrow down into the soul of our work because it is there that we find the stuff that bonds us together in a common cause. That is why we asked Judy to share the story of her journey with Gregory from a Mother's perspective. If you are unfamiliar with this story, reading it will not only change your perspective of Judy, but challenge you to look again at both those we serve and those that serve them.

## Up until 10 months of age, Gregory progressed normally:

he began walking, waved bye-bye and was curious about and pointed at things while looking to us to name them. Our nightmare began in the month after he was ill from his vaccinations, when one afternoon we joined other families who'd been in our Lamaze birthing class. There we discovered that Greg was not interested in the other children or toys and didn't even interact with us in the same way the others did with their parents. The next month he began having what we'd later learn were myoclonic seizures but at the time appeared to be just "head drops" while sitting in his high chair. By his annual well-baby check-up the next month these were occurring multiple times a day. The pediatrician assured us that we shouldn't worry about these episodes because "he'd grow out of them" and a psychologist assured us that babies have different rates of growth in their sociability.

The next couple of months were filled with uncertainty and fear as his seizures increased in severity and frequency and his skills appeared to decrease, yet the doctor claimed it was nothing to worry about. It was by chance that my husband mentioned Greg's episodes to his director who coincidentally was the former head of a national epilepsy organization. He immediately recognized the seriousness

of the problem and got us an appointment at the Epilepsy Foundation of Michigan where on March 15th Greg was diagnosed with hypsarrhythmia and myoclonic seizures. ([http://professionals.epilepsy.com/page/syndromes\\_spasms.html](http://professionals.epilepsy.com/page/syndromes_spasms.html)) On that day, the doctors told us that there was little chance of controlling these kinds of seizures, and that they caused brain damage as they occurred, thus the likelihood that he would be mentally retarded. We spent the next several months giving him daily ACTH injections that were a successful intervention for some children, but ultimately, not for Greg. I was 8 months pregnant with our second child, when I took Greg in for an 18-month "well-baby" check up with another pediatrician who told me that Greg was definitely developmentally delayed.



The next several months were a mix of grieving for Greg and the joy of our newborn. For Greg there was experimentation with cocktails of anticonvulsants, frequent visits to Children's Hospital in Detroit, assessments of the extent of his developmental delays and for us, decisions about interventions. After a couple of unsuccessful attempts of integrating him into regular pre-schools, we settled on an autism program called "Project Sunrise" run by the intermediate school district. In his 20 years of special education, that

program was the only one where we saw him acquire skills (e.g. signing, roller skating) partly due to small classroom size (8 students) and the high staff to student ratio (1:1). The program was dismantled after five years after which he was placed in a larger classroom of students with physical and intellectual disabilities and a lower staff to student ratio. It was in these classrooms that we saw an increase in his behaviors, an increase in the use of restraint and seclusion, and a decrease in his skill acquisition rate.

As a family we tried valiantly to be "normal." The four of us went camping, to the beach, the park, the zoo, and out to eat; visited family and friends; and went on some great vacations. Still, our daily lives were marked with hypervigilance since Greg continued to have daily seizures that threw him to the floor despite the medications; and he actively sought stimulation by running, balancing on the edge of steps, and getting his hands in all manner of

*(continued on back cover)*

# A Personal Journey to Recovery

*"Ours is a Cause of Life and Death"*  
–Senator Gordon Smith

Marlene Lawrence, RN, BSN, CPSS, PATH Master Trainer

## Personal Journey

I knew for years that something was wrong. The first time I woke myself up screaming in the night was 1992. Because I refused to have a mental illness, due to the stigma, I approached the system only when absolutely necessary. I needed help sleeping and told a psychiatrist just enough to get medications to sleep. By 2002 I was psychotic and began making bad decisions.

I voluntarily went into a psychiatric hospital but after a botched escape attempt my children had me court ordered to stay in the hospital. After discharge I felt like my life was over. The majority of the time I spent in my home, marking time by the show that was on television. If *Murder She Wrote* was on, I knew it was 10 a.m. on a week day. That's not a very pretty life, in anyone's imagination.

## Employment Journey

I began to receive my mental health care at Summit Pointe. They gave me encouragement and the opportunity to work at the Drop In Center in Battle Creek (SHARE Center). I knew that if they believed I could do it, then so did I. I began to hope – the essential component of recovery. Hope is not just a noun, it is a verb! It is about desiring something that you believe is possible to achieve or fulfill. It is longing for some-

thing you believe is obtainable. Hope is the flame that kindles your spirit; that enables you to move out into the world to make a difference. With this new energy, I acquired training through the Michigan Department of Community Health to become a Certified Peer Support Specialist. Share Center has given me the opportunity to use these skills as its director.

## Recovery Council Journey

One of the significant things for my growth as a Certified Peer Support Specialist was being appointed by MDCH to serve on the Michigan Recovery Council representing Health and Wellness. It was at the meetings that I learned about the endless possibilities. By working together, we can change the status quo. We can change the system so we do not continue to die 25 years earlier than the general population. It was there that I learned that *"Ours is a Cause of Life and Death."*

It was there that I realized what it will take to speak with one voice to improve our odds. But that is what we must do! It was there that I realized that Recovery can be measured. I learned ways to work and share together, and what it takes to achieve system transformation. I learned to speak out about issues of mental health and recovery. I learned that sometimes it takes a soft voice and sometimes it takes a loud voice. But most of all, our voice must be heard. ■

## Michigan Association of CMH Boards Annual Winter Conference

### Circles of Support...Engaging the Community

February 23 & 24, 2010 • Lansing Center/Radisson Hotel, Lansing, Michigan  
Pre-Conference Institutes on February 22, 2010

#### 2010 Winter Conference Goals

- Encourage consumer connections to the community through schools, social networking groups, cultural and spiritual activities, and employment opportunities
- Emphasize programs that promote inclusion into the larger community and end isolation
- Highlight community resources that are available for consumers and their families
- Enhance building relationships with advocacy partners and legislators

#### Plenary Sessions Include

- “**Implications of Healthcare Reform for the Behavioral Healthcare System**” – Charles Ingoglia, Vice President of Policy, National Council for Community Behavioral Healthcare
- “**Recreating Intentional Community**” – Amy Long, Educator/Training, National Empowerment Center
- “**Key Issues Update from Michigan Department of Community Health Deputy Director**” – Michael Head, Director, Mental Health & Substance Abuse Administration, Department of Community Health
- “**Everyone Succeeds when Everyone Belongs**” – Norman Kunc, Broadreach Training and Resources

Complete conference information available at [www.macmhb.org](http://www.macmhb.org) or by calling 517-374-6848

Sherri Rushman

As I began talking to audiences about the process of my recovery from mental illness, it became very clear that so many of my desired goals were achieved because of the many Hope Givers in my life. Hope Givers are the folks who provide hope and support. They believe in people and see potential for success and achievement. I also began to see that my part in the process was to become willing to be a Hope Receiver. Hope Receivers accept hope and support. They take action steps to achieve personal or professional goals. Hope Receivers gain confidence and motivation from support provided by Hope Givers.

Think about it. Whether you have a mental illness or not, you have undoubtedly been both a Hope Giver and a Hope Receiver at some time in your life. Perhaps, like me, you also have noticed that there are people around you who play the roles of Hope Stealers. Hope Stealers fail to see an individual's full potential and tell them that they can't or are not qualified to achieve a goal. In order for my recovery to move forward, I had to get pretty savvy about identifying such people and learning how to ignore those "Hope Stealer" influences. I gained courage, confidence and strength by setting out to prove that my Hope Stealers were wrong.

Here's just one example. After my divorce, I wanted to return to college even though I had been told that I had a mental illness. In fact, when I went to a mental health agency for career counseling and college assessment, I was diagnosed with paranoid schizophrenia because I had been experiencing delusional thinking. Their report was that not only could I not get a college degree, but I couldn't even pass a college exam. I didn't know what to think about that at the time, but now I recognize them (and I hope you do too) as Primary, First Degree Hope Stealers!

But fortunately I had enough Hope Givers to encourage me at that difficult time. My parents insisted that I could do whatever I wanted to, even with my mental illness. They encouraged me to apply to a college. I forged ahead; made an appointment with the admissions office at Oakland University in Rochester Michigan. Not only was I accepted, but they also allowed a transfer of a full year's academic credit that I had earned when I attended Michigan State just after high school graduation!

College was not easy for me. After all, in addition to my disability, I was a single mother with three small sons. Sometimes I had to take incompletes in classes, but I was making progress. But alas! As these things go with lots of stress, one day my medications stopped working. Life was just too overwhelming and I was hospitalized for 6 weeks. By caring for my children,

my sister became a most valuable Hope Giver by her deeds, not her words! But there were some hospital staff who told me that if I didn't improve I would be put in an institution. So I learned to not talk about my delusions. I was released from the hospital but was feeling pretty hopeless about continuing my goal of finishing college.

How fortunate for me that when I gathered my courage to try again, the first person I encountered turned out to be just the Hope Giver I needed. This human resource class professor told me, "Sherri, you have the right stuff to become the mental health trainer that you have been dreaming of becoming and I will help you do it!" Now I became a Hope Receiver again as I signed up for his next class. My first assignment was to bring in my high school yearbooks the first day of class. He took a look at them and said, "Oh, I see you were in a speech contest and the school plays...and here's a photo of you dancing in a talent show...and look at this, swim team too!" By showing me my own past accomplishments, he reinforced for me the certainty that indeed I had the personal experience to become a mental health motivational speaker. There were ups and downs during my college career, but I did receive my degree in Human Resource Development- with an emphasis in training- in just a year and a half after the hospitalization.

So you can see that it pays to be a Hope Receiver. Look for the many Hope Givers around you. Listen to them and take action on the visions they can see for you. Before long you will then become a Hope Giver. And don't forget. Be on the lookout for those sneaky Hope Stealers! You can avoid their slings and arrows if you see through their game!

I'm writing a book called *CATCHING HOPE* (Hope Givers, Hope Receivers and Hope Stealers). I'm looking for people who would like to be in my book by telling their story which would include their Hope Givers, how they have been a Hope Receiver, and how they ignored Hope Stealers. I also have a web site at [www.catchinghope.com](http://www.catchinghope.com) where you can see events I have been speaking at. You also can send e-mail inquiries to [Sherri@catchinghope.com](mailto:Sherri@catchinghope.com). Now go and be Hope Givers! ■

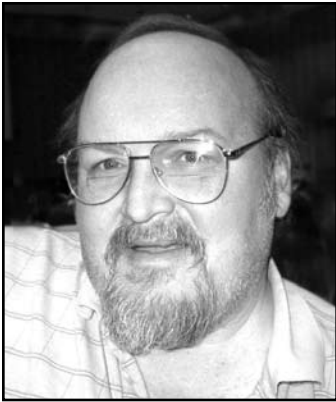
*Sherri Rushman is a Consumer Education Specialist with the Oakland County Community Mental Health Authority.*



# Ten Fundamental Components of Recovery

Substance Abuse and Mental Health Services Administration (SAMSHA)

- 1 Self-Direction:** Consumers lead, control, exercise choice over, and determine their own path of recovery by optimizing autonomy, independence, and control of resources to achieve a self-determined life. By definition, the recovery process must be self-directed by the individual, who defines his or her own life goals and designs a unique path towards those goals.
- 2 Individualized and Person-Centered:** There are multiple pathways to recovery based on an individual's unique strengths and resiliencies as well as his or her needs, preferences, experiences (including past trauma), and cultural background in all of its diverse representations. Individuals also identify recovery as being an ongoing journey and an end result as well as an overall paradigm for achieving wellness and optimal mental health.
- 3 Empowerment:** Consumers have the authority to choose from a range of options and to participate in all decisions—including the allocation of resources—that will affect their lives, and are educated and supported in so doing. They have the ability to join with other consumers to collectively and effectively speak for themselves about their needs, wants, desires, and aspirations. Through empowerment, an individual gains control of his or her own destiny and influences the organizational and societal structures in his or her life.
- 4 Holistic:** Recovery encompasses an individual's whole life, including mind, body, spirit, and community; and embraces all aspects of life, including housing, employment, education, mental health and healthcare treatment and services, complementary and naturalistic services, addictions treatment, spirituality, creativity, social networks, community participation, and family supports as determined by the person. Families, providers, organizations, systems, communities, and society play crucial roles in creating and maintaining meaningful opportunities for consumer access to these supports.
- 5 Non-Linear:** Recovery is not a step-by-step process but one based on continual growth, occasional setbacks, and learning from experience. Recovery begins with an initial stage of awareness in which a person recognizes that positive change is possible. This awareness enables the consumer to move on to fully engage in the work of recovery.
- 6 Strengths-Based:** Recovery focuses on valuing and building on the multiple capacities, talents, coping abilities, and inherent worth of individuals. By building on these strengths, consumers leave stymied life roles behind and engage in new life roles (e.g., partner, caregiver, friend, student, employee). The process of recovery moves forward through interaction with others in supportive, trust-based relationships.
- 7 Peer Support:** Mutual support—including the sharing of experiential knowledge and skills and social learning—plays an invaluable role in recovery. Consumers encourage and engage other consumers in recovery and provide each other with a sense of belonging, supportive relationships, valued roles, and community.
- 8 Respect:** Community, system, and societal acceptance and appreciation of consumers—including protecting their rights and eliminating discrimination and stigma—are crucial in achieving recovery. Self-acceptance and regaining belief in one's self are particularly vital. Respect ensures the inclusion and full participation of consumers in all aspects of their lives.
- 9 Responsibility:** Consumers have a personal responsibility for their own self-care and journeys of recovery. Taking steps towards their goals may require great courage. Consumers must strive to understand and give meaning to their experiences and identify coping strategies and healing processes to promote their own wellness.
- 10 Hope:** Recovery provides the essential and motivating message of a better future—that people can and do overcome the barriers and obstacles that confront them. Hope is internalized but can be fostered by peers, families, friends, providers, and others. Hope is the catalyst of recovery. Recovery not only benefits individuals with mental health disabilities by focusing on their abilities to live, work, learn, and fully participate in our society, but also enriches the texture of American community life. America reaps the benefits of contributions that individuals with mental disabilities can make, ultimately becoming a stronger and healthier nation.



## THE STRUGGLE FOR ESTEEM

Duane Gaultney with Clint Galloway

*Duane Gaultney, a board member of Community Mental Health Services of Muskegon County, has become a familiar face and voice at MACMHB conferences, Executive Board, Steering Committee, and in the Contract and Financial Issues (CFI) meetings. It hasn't always been that way.*

*Duane has wanted to share his story with others but felt he didn't have the writing skills to communicate the message. I suggested an interview format and he agreed. A few moments after the interview began I realized I was not listening to the person I came to interview! As the stories emerged, my image of Duane was being transformed. Suffice it to say, I will never hear the same "Duane" again. Is this not true of every acquaintance as long as we remain ignorant of the path they have traversed to our place of meeting? —C.G.*

**Connections:** *Duane, let's start at the beginning. Tell me about your childhood.*

**Duane:** As a child, I knew something was different about me. I didn't have friends...I talked too much. I would go on and on and on. People didn't like to be with me and I didn't know why. Now I know why. It was my mania. But I have to admit, I wanted to be away from everybody and everything.

**Connections:** *When did you learn you might have a mental illness?*

**Duane:** I was 16 years old and in high school. I attempted suicide. That was my first attempt. By the time I was 28, I had tried suicide 28 times! I remember thinking that on my 28th birthday.

**Connections:** *When did it sink in that you had a serious mental illness that needed treatment?*

**Duane:** I had made another suicide attempt and was taken to the emergency room. The doctor sewed me up and was ready to send me back home. I said, "Wait a minute! No! Something's not right." So they sent me to CMH. I was diagnosed as being bi-polar.

**Connections:** *Then what happened.*

**Duane:** I was hospitalized in Traverse City [State Hospital].

**Connections:** *Can you describe your experience there?*

**Duane:** That was the worst year of my life! I was so doped up. I didn't know what was up nor what I was doing. They gave me shock treatments. I would never wish that on anybody!

**Connections:** *What happened after you were released?*

**Duane:** Within 2 months after being released I joined the Navy.

**Connections:** *How did you manage that?*

**Duane:** I fibbed a little and did real well at hiding my illness. I did that a lot. A lot of people with a mental illness learn to do that.

**Connections:** *And your experience in the Navy?*

**Duane:** Well, it wasn't all bad. I was in it for ten years. But can you imagine being bi-polar and stuck on a ship? I did a lot of walking! I nearly wore out every inch of that ship. It was 180 feet from the top of the Crow's Nest to the bottom of the Hold and 311 feet from Bow to Stern. I knew it real well!

**Connections:** *Did you take medications for your illness while you were in the Navy?*

**Duane:** No, I just did a lot of pacing.

**Connections:** *Why did you leave the Navy?*

**Duane:** I tried suicide again and they gave me a medical discharge, and within a year I was back in Muskegon Community Mental Health. Things started turning around for me.

**Connections:** *How so?*

**Duane:** It started when Richard Wellwood came in and talked about drop-in centers to our CMH. They picked out some consumers and we spent about a month looking at slides and learning how it works. I was elected as a co-director and later as the director. It was called *Unlimited Potentials*. I started working on advocacy with some of the consumers. We worked with CMH and participated in some of their workshops. Then Adonica Kunnen, an employee at CMH, told me there was an opening on the Board and that I should apply. I was interviewed and appointed to the board. A little later I started attending the CFI meetings at MACMHB, and next thing I knew I was asked to be the board member co-chair. I think I was one of the first, if not the first, consumer to become a co-chair of a MACMHB standing committee.

**Connections:** *What has all this meant to you?*

**Duane:** It has really changed my life! Before becoming involved I was basically looked upon as someone who was sick and didn't know what I was talking about. Now people listen, and doors have opened. People know who I am and say, "Hi!" And that makes me feel good and welcomed, like I've earned my own way.

**Connections:** *What have you learned as a CMH board member?*

**Duane:** A lot! I've learned it's OK to ask questions. If you ask the questions, you get the information. And I've started to look for what other people need—not just me. I've learned to look at the other side of the fence, the different pots of money, where the money is coming from, and where it goes; why some programs get cut. Sometimes it seems like a game, but it's not all a bad game.

**Connections:** *What final thoughts would you like to share?*

**Duane:** I'd like to thank the people who have really helped me. I wouldn't be here if it wasn't for Adonica. She really opened the doors. She believed in me. The directors at Muskegon CMH have all helped me. I like to say that Jim Borushko molded me, Jim Elwell sculpted me, and John North is polishing me. Also, I need to thank Bob Sheehan who gave me the opportunity to be the co-chair of CFI. This means a lot! All of this has given me a lot of esteem and people with mental illness struggle with that. ■



MACMHB  
426 S WALNUT  
LANSING MI 48933  
Telephone: 517-374-6848  
www.macmhb.org

Non-Profit Org.  
U.S. Postage  
PAID  
Lansing, MI  
Permit No. 504

Got something to say? Send it to us. You might get published! And please, tell us what you think about your newsletter.  
E-mail your feedback, questions, submission ideas to: [macmhconnections@gmail.com](mailto:macmhconnections@gmail.com)

*Connections* is published three times a year by the Michigan Association of Community Mental Health Boards • All Rights Reserved

### *A Mother's Perspective* (continued from page 3)

gooey things. And we lived with a fairly rigid schedule of medication administration, feedings, diaper changes, and bedtimes. We volunteered frequently in his classroom, and at home tried to implement the interventions we learned there, but with frustratingly little outcome. Thus, we began using community mental health's respite care services early and frequently to give my husband and I a break both with or without Greg's sister. I found too that the greatest help to me initially was meeting weekly for coffee with the seven other mothers of his classmates. We talked about our children, our lives, and our joys and frustrations. It was during this time that I recognized the importance of families getting support while they are care-giving, and that resulted in my getting involved in local and state advocacy organizations and efforts (e.g. passage of the Family Support Subsidy) and later in returning for my masters' degree in social work.

When Greg was 17, it became clear that the undivided attention and care he required of us was having a seriously negative impact on his 16 year old sister. While we had in-home assistance after school five days a week it was just not enough help. We talked to the CMH about options: more respite, Children's Waiver, and a shared arrangement with a family foster care home. When CMH told us that Greg would have a better shot at getting immediately into adult programs after "graduating" special education if he were in the foster care system, we reluctantly settled on that option. So for the next four years Greg stayed during the week with the foster family, and came home to us on Friday after school for the weekend. A succession of burned-out foster families together with Greg's increased physical fragility led us to place him into a six-bed AIS home in his last year. He was lucky to have his own room which we

enjoyed decorating for him and he seemed well-loved by the staff. He continued to come home most weekends, to visit family, and to vacation with us.

In an attempt to address his frequent upper respiratory problems, we were advised that he should have a tonsillectomy. A simple outpatient procedure turned into the final nightmare of his life when he acquired an infection at the hospital and died of pneumonia a week later. He was 23 years old.

Greg never learned to speak words and his signing remained at a rudimentary level, but his vocalizations, looks and actions spoke volumes. He did not reach out to others but he welcomed affection and attention. His frustrations were expressed in biting himself, but never others. He loved to swing under our big backyard maple tree with the breeze in his face. He was a gentle soul.

Living with, caring for, and loving Greg are the foundation of my work. What I can no longer do for him, I can do for others like him, and their families. I learned lessons from my mistakes with him, and with his sister, that I can't fix retro-actively, but can make sure that other families and caregivers have the information:

1. Assume that the individual can do and be more than is apparent. Don't get distracted by the DISability.
2. Smaller settings for learning and living are always better than larger, and individualized attention is always better than attention divided six, eight or ten ways.
3. All family members need TLC and support all the time, and sometimes they need professional help, even if they aren't acting out or acting bad.
4. Take time each day to appreciate and celebrate the individual's gifts...a life can be short. ■