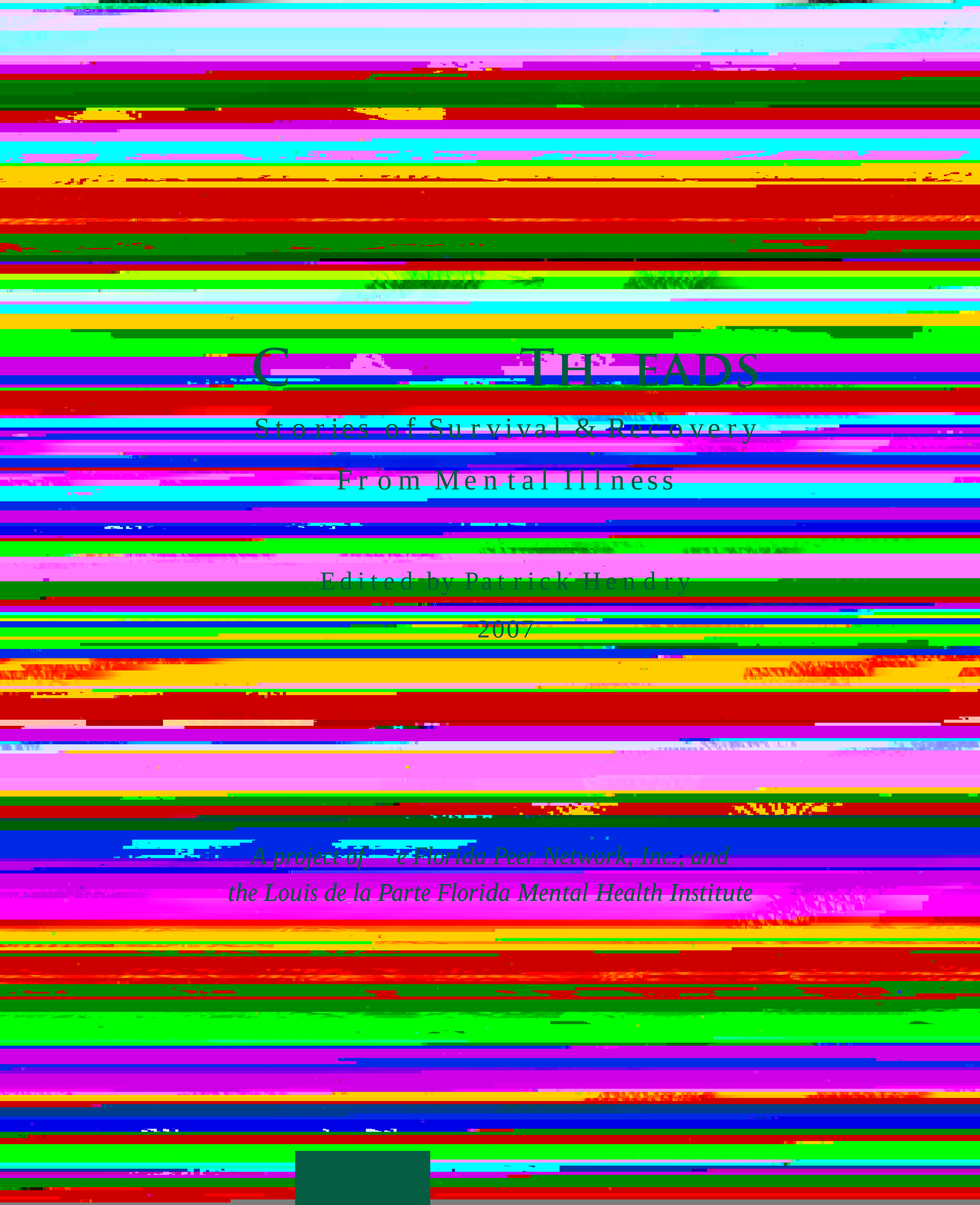

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Stories of Survival & Recovery
From Mental Illness

Edited by Patrick Hendry

2007

A project of the Florida Peer Network, Inc., and
the Louis de la Parte Florida Mental Health Institute

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Foreword

The reader is probably curious to learn what a person with mental illness is like. Who are these people? In what way are they ill, and what makes them different from the rest of us? What can be done to help? Is it really possible to recover from mental illness? How would I know if I were mentally ill myself?

I always wondered those things, too. I remember when I was in junior high school, I sometimes called myself “crazy,” and I joked about how the little men in white coats were going to come and take me away. In high school, my friends and I frequently called each other “nuts,” and it was a term of endearment, almost a compliment. When I was in college, however, madness ceased to be a joke because I myself was diagnosed as mentally ill. Now, many years later, I have recovered from mental illness, but I know that I will always be crazy.

This book suggests some answers to our natural curiosity about mental illness. The authors of these stories of recovery are all people who have experienced mental illness, and they are all residents of the state of Florida. But they are all different. Some of the storytellers first experienced a psychiatric disability as a child; others were not diagnosed until later in life. Some talk about what it feels like to be depressed, hear voices, or struggle with addiction, and some talk about how physical abuse or a traumatic event led to psychiatric problems. For some people, mental illness brought with it unemployment, extreme poverty, and even homelessness. Yet some of our authors creatively pursued the arts even while dealing with mental distress, and some achieved remarkable success in professional careers or in the armed forces.

Their accounts of recovery are also varied. Some people seem to follow a personal path of discovery from the start, whereas others ws0(et ex natSdom[(people, mes Tm 0.002 Tc 0 Tw [(F)f FlsoSd
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NAMI), and thnMmental HMHA).? However, our storytellers

peer specialists employed in all aspects of the mental health system. Peer specialists are persons recovering from mental illness who provide support and advocacy to their peers—to other persons who have had similar experiences. As it was for Dixie Merchant, working as a peer specialist can become a "joyful life's pursuit," one that maintains one's own recovery and facilitates recovery for other people as well.

In addition to filling the newly certified positions of peer specialists within

Acknowledgments

This book has been a very important and exciting project for the Florida Peer Network. Our mission is to promote recovery, quality of life, advocacy, education, mutual support, peer-directed services, and participation in mental health policy design for consumers throughout the state of Florida, and this book contributes directly towards that mission.

I want to thank Mark Engelhardt, MS, MSW, ACSW, faculty member of the University of South Florida (USF) and Florida's Olmstead grant coordinator, in the Department of Mental Health, Law and Policy and the Louis de la Parte Florida Mental Health Institute (FMHI) at USF for this unique opportunity to gather the stories of our members to tell their tales of recovery. Mark's belief in us as representatives of the consumer/survivor community is a wonderful example of the working nature of the peer/professional relationship. Without Mark's support, this project would never have come to fruition. Thank you, Mark, for all that you have done and continue to do.

I also wish to thank FMHI, through Florida's Olmstead Grant, for providing the financial support so necessary to producing this document. The principles supported in the Olmstead decision are the cornerstones of the consumer/survivor mission of achieving independence and self-determination in the community.

I want to thank Sally Clay for her support and wisdom in approaching this project. Sally represents the finest qualities of the consumer movement, and her technical assistance has been invaluable. I particularly wish to thank her for agreeing to write the forward to this book and for telling her own story of survival and recovery for the benefit of our readers.

There are many people whose ideas have guided my development as an advocate for improving the mental health care system in this country. Their stories are part of this document—Jeffrey Ryan, Bill Schneider, and Clint Rayner in particular. Special thanks go to the founding mother of the Florida Peer Network, Gayle Bluebird. Other most important influences include Pamela Baker; Tom Lane; Kathryn Hunter; and my favorite author in the field of mental health care, Paul Carling.

As always, the Florida Peer Network wishes to thank the Advocacy Center for Persons with Disabilities, the protection and advocacy organization of Florida. Its assistance in the formation of the Network and continued support have been the lifeblood of our organization. We particularly want to thank our guru and protector at the center, Dana Farmer.

And, above all, I wish to thank my wife, Keri Reyburn, MEd, for her support, knowledge, and insightful and frequent challenges to my day-to-day thinking in approaching these complex issues.

Patrick Hendry, Executive Director, The Florida Peer Network

Introduction

Common Threads for Recovery

Recovery. It is such a simple word, simple but elegant. For those of us experiencing the symptoms, trauma, poverty, and isolation that come from living with a major mental illness, that simple, elegant word is a godsend. Most of us were given a very different message when we were first diagnosed. The message was one of hopelessness, loss, and despair. We were told that our illnesses would be lifelong, that we would nevep6us experienceiommon nevepfraid toivari

It All Begins With Rights

Olmstead v. L.C. and E.W.

On June 22, 1999, the Supreme Court of the United States rejected the state of Georgia's appeal to enforce institutionalization of individuals with disabilities and affirmed the right of these individuals to live in their communities. Olmstead v. L.C and E.W.

Justice Ruth Bader Ginsberg, in delivering the opinion of the court, wrote "Under Title II of the federal Americans with Disabilities Act, states are required to place persons with mental disabilities in community settings rather than in institutions when the State's treatment professionals have determined that community placement is appropriate, the transfer from institutional care to a less restrictive setting is not opposed by the affected individual, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities."

This decision enforced and accelerated the trend towards deinstitutionalization in the treatment of mental illness. Thousands of Americans in hospitals around the country had the right to live in the community and receive the services they need reaffirmed. State after state began to look at the way these services are delivered and begin the process of transforming their systems of care to a recovery-based model. No longer would people with psychiatric disabilities be looked at as simply patients; they were now recognized as people with the same hopes and dreams as others. Supported housing, community-based services, peer and family supports, access to medications, livable incomes, and meaningful work became the watchwords of state-run mental health care systems.

In a letter to each state's Medicaid director, the Health Care Financing Administration, now known as the Center for Medicare and Medicaid Services, set guidelines to comply with the decision. According to the Substance Abuse and Mental Health Service Administration's Community Integration Now! Community Involvement in State Community Integration Planning Under the Olmstead Decision (2002), this letter included the following principles recommending in part that each state's plan should:

- "Ensure the transition of qualified individuals into community-based settings at a reasonable pace.
- Ensure that an assessment process determines how community living might be possible (without limiting consideration to what is currently available in the community).
- Evaluate the adequacy with which the state is conducting thorough, objective and periodic reviews of all individuals with disabilities in institutional settings (such as state institutions, mental retardation centers, nursing homes, psychiatric hospitals, and residential service facilities for children) to determine the extent to which they can and should receive services in a more integrated setting.
- Involve people with disabilities (and their representatives, when appropriate) in the plan development and implementation process.

- Determine how many individuals with disabilities are currently institutionalized and are eligible for services in community-based settings, and consider better ways to collect information.
- Identify what community-based services are available in the state, assess the extent to which these programs are able to serve people in the most integrated setting appropriate, and identify what improvements are needed to make the system better and more comprehensive.
- Review what funding sources are available (both Medicaid and other funding sources) to increase the availability of community-based services."

Community Integration

In the 1990s, the traditional community mental health system faced the dedication and energy of a growing consumer/survivor movement over the battlefield of self determination and integration. This battle drew much of its inspiration from the larger disability community and the ongoing civil rights movement. The behavioral health care system lagged far behind other public health systems in providing individuals with treatment and supports in the community. Although many states had begun the process of removing people from large institutions in the 1970s, most had not yet established the necessary supports for those same people to live successfully in the community. Proponents of community integration believe in the basic right of all people, including those with psychiatric disabilities, to live in the community of their choice and to participate in day-to-day activities as full members of society.

Taylor, Racino, Knoll, and Lutfiyya (1987) described the following principles as essential to the concept of community integration:

- All people, regardless of differences, deserve a chance to live in the community.
- People with differences can be integrated into neighborhoods, employment opportunities, and social situations in the community.
- All people and their families need support; this support should be provided in the community where people work and live, not just in professional settings for people who are "different."
- It is important that people develop social relationships with people with and without labels.
- People with and without those labels can learn from one another.
- People who use services and their families should be involved in the planning, design, implementation, and evaluation of those services. It is also important to develop mechanisms for them to hold the services accountable.

Paul J. Carling (1995), in his seminal work Return to Community: Building Support Se1.5367J -7 TD [(S)(e ed arn fr)6aset) deI19ous the s semina1(eev)6(elop social r)10(ela

- People's needs change over time; hence, services and supports should be available at varying levels of support for as long as a person needs them, and regardless of where the person lives.
- People's relationships with service providers also change over time, so that continued access to housing, work situations, or social networks should not depend on whether or not a person is 'getting along' with a service provider.
- Family members of a person with a psychiatric disability require and deserve substantial support if they are to provide support to their disabled relative and meet their own needs in the process.
- Family members should not be blamed for their relative's disability but, instead, should be treated with the same respect that all citizens deserve, and with the high level of involvement and support that they deserve as well.
- The legitimate target of family advocacy is for family needs; the fundamental power over services should rest with the individual who has the disability."

Consumer/survivor organizations understood very quickly that, to succeed, people need more than traditional psychiatric services. The isolation and economic deprivation that comes with living with mental illness create a wide range of related problems that must be solved to make the successful transition to living on one's own. Housing, employment, relationships, education, and physical health are only some of the needs that must be addressed to succeed. This does not mean that traditional mental health services do not play a major role in helping people deal with their illnesses; rather, it accentuates that these services need to be tailored specifically to meet the needs of the individual and be offered in a community setting. Recent innovative ideas such as the Florida Self-Directed Care model focus on the principles of self-determination, community integration, and true person-centered planning. It is a perfect example of how the public mental health system can adapt to the need for recovery-based services to be available in community settings.

So, how will this goal of community integration, outlined in the Olmstead decision and the Americans with Disabilities Act and articulated by consumer groups around the nation, be achieved? According to Carling (1995):

> It will be achieved by vastly increasing the availability of stable, affordable housing that is physically integrated. It will be achieved by creating access to employment in genuinely integrated work sites, rather than in transitional or sheltered, segregated settings. It will be achieved by arranging support through freely given, non paid relationships with non disabled citizens, rather than assuming that all needs are to be met through a professional service system. It will be achieved by making services available that are both flexible and reliable, rather than forcing individuals to fit into program 'slots,' or even into programs at all. It will be achieved by basing all decisions about housing, work, social networks, and services on each individual's choices, goals and needs. Finally, it will be achieved by developing and funding services operated by people with disabilities, and by transferring decision making about policies, programs, staffing, and the actual resources for services (including funding), to these people.

It requires a whole new way of looking at the service delivery system and the nature of the relationship between those funding services and those receiving them. For too long, our system has looked at people with psychiatric disabilities as helpless, needy, and unable to make meaningful choices and participate in their own treatment. But the experiences of thousands of individuals who have regained control of their lives belie that notion. Illness does not always equate to incompetence and inability, and by sharing our experiences with recovery, we demonstrate the strength and knowledge we have gained. Even in our partnerships with family and friends, it is important to remember that our voices as people in recovery are the most important single element in the equation.

> The progressive collective minds of our mental health system have slowly, by degrees, crept toward the realization that what is good for everyone – what people around the world have fought and died for, what civil rights movements have struggled for – is also good for mental health consumers. I remember a sign at one of our rallies: 'Freedom is the Best Therapy'. Freedom of choice, independence, self-determination and empowerment are what are best for us.

Howie the Harp
in Carling (1995)

Stories of Survival & Recovery

Finding Purpose Through Advocacy

Jeffrey Ryan has been a powerful force for advocacy in the Florida mental health community for many years. While finding his way down the confusing path to his own recovery, he has helped scores of fellow consumers fight for their dignity and rights. In 1992, he co-founded the Mindmenders Foundation, the first consumer/survivor organization in Florida to contract with the state to provide peer-run services.

Jeffrey's story of illness and history of treatment begins in childhood at a time when mental health services were often harsh and damaging. He identifies a number of themes important in his recovery and that of others. He speaks about the importance of person centered services, peer support, meaningful activity, and creative outlets. He also speaks of the benefits of companionship, education, quality psychiatric services, responsibility, and advocacy. Jeffrey describes the positive nature of the Self-Directed Care model and the effect it has had on his life in recovery.

Jeffrey Ryan's Journey to Wellness and Recovery

I was raised in Long Island, NY. I was a relatively active child and had difficulty sitting still in school; I was bored with school and did much better with hands-on learning. When I was in my early teens, I started to hear a voice giving me commands. I was convinced God was talking to me. For example, God told me to go to Florida and start a civil rights movement, so I took my father's credit card and flew to Florida, where I was arrested for inciting to riot and disturbing the peace. I had several other episodes and wound up taking a lot of different trips in those years. Once I tried to ride my bicycle to Washington, DC, to speak to the President, but I was picked up in Maryland. On a subsequent attempt to visit and speak with the President, I was picked up by the New York City Police after riding my bicycle through the Holland Tunnel, and I refused to tell them my name because I was told by God that if they knew who I was, they would kill me. I had not committed any crime, and the police knew I was delusional, so they sent me to Bellevue Hospital. I remained there for 10 days before my parents were able to locate me.

At age 13, I began to have auditory hallucinations telling me to kill myself, so I overdosed on pills. At the local hospital, it was decided for my safety that I be sent to long-term care. I was committed to a state hospital, where I was kept for 9 months. In the early 1960s, there was no children's unit; therefore, I was housed in an adult unit with approximately 40 residents. Besides me, there were 4 other children on the unit. I was diagnosed with paranoid schizophrenia and received several different kinds of medication. I also received electroconvulsive therapy and hydrotherapy. At that time, the medicines of choice were chlorpromazine (Thorazine), trifluoperazine (Stelazine), and thioridazine (Mellaril). The side effects having bipolar disorder with psychotic features. In addition to the other medicines, I started taking lithium, which helped me quite a bit. However, I still couldn’t change my addiction to drugs and alcohol, and the use of these substances only seemed to create havoc in my life. It wasn’t until the mid 1980s that I found really positive treatment after I became involved with a support group run for anyone who was having mental health problems. While attending this group, I found other partner will be the first important step in gaining recovery and wellness. If your doctor refuses to accept that you are the central player in your treatment team, I encourage you to consider your treatment options and perhaps find a new doctor. I know that treatment options are severally limited for many people in our area, as well as in the nation. For this reason, I often hesitate to suggest changing doctors, but when a doctor does more harm than good, we simply must find new options.

Second, we've all been told that we're not well enough to do too much of anything because of our illness. This belief has no merit at all. I found the more I became involved in my advocacy, the more healthy I became because I had given purpose to my life and I thought about what I was doing more than I thought about my illness. I'm not suggesting full-time jobs for everyone; what I am suggesting is to get out and do something productive with yourself by working or volunteering. One of the most difficult things I had to do many years ago was to get myself out of my house because I had isolated myself for so long that I became more comfortable not seeing anyone or anything. I spent a total of 4 years not going out of my house. I took a volunteer job cleaning cages at a local wildlife rehabilitation center for 1 hour a week. That was difficult for me, but in a short time I was doing several hours a week. This ultimately led to my becoming involved in my mental health advocacy full time. My life began to have meaning and purpose again.

Currently, I maintain my wellness largely because of my companion psychiatric service dog, Rylee, whom I must care for regardless of how I'm feeling. She gives me the structure in my life I need by taking care of her, walking, feeding, and bathing—not to mention that she's become my constant companion. She's always available to talk to when I'm not feeling all that well. She's made it possible for me to travel to many meetings across the country. Every day, Rylee continues to be a very important part of my wellness and stability.

Finally, my involvement with self-directed care has given me the opportunity to start working with my creative talents again, something I have longed for since my school days. I have started with photography by going back to school and asking for the tools I needed to pursue this endeavor. Of all the things I've done during the years, this has brought me the most amount of satisfaction and happiness. This experience not only has helped me in my recovery and helped me maintain my mental health stability, but it has also brought me back to 1970, when my life changed direction so radically. As time goes by, I'm hoping to devote more and more time to my art and creative talents.

I have shared my story with you in hopes of giving others who live with psychiatric disabilities the knowledge that they are not alone and that there is hope for the future. The strategies that have worked for me may not work for everyone, but parts of them and those of others will help you find your correct path. Recovery is possible, and there is no shame in having a brain disease; all it takes is an effort on your part. My road to wellness hasn't been an easy one, and I've fallen down many times. With the support of others and continued education, I'll continue my road in recovery. And by no means is this story complete; every day I learn something new from others that I'm able to apply to my own life.

Jeffrey Ryan

- **"Empowerment.** Rather than a professional deciding what is best, the consumer should be involved in all treatment decisions. An equal partnership replaces the power differential found in traditional mental health systems—an ideal based on the philosophy that in peer-run services, everyone should be equal. True empowerment comes from the individual, but systems can remove barriers to empowerment.
- **Recovery.** Advocates have been pushing mental health systems to make changes based on the recognition that people do recover from mental illnesses. In order to address the multiple effects of mental illness, a recovery focused mental health system recognizes that consumers hold the key to recovery. Clinical mental health services alone do not lead to recovery; natural supports, such as families, friends and recreation are important (Anthony, 1993).
- **Consumer-centered outcomes.** Traditionally, the mental health system has focused on clinical outcomes, or measuring the severity of a person's symptoms. This approach relies on clinicians' views of success, rather than the consumers' view of what is important. Consumers have been advocating for mental health systems to use outcomes that are person-based rather than illness-based.

Voluntary participation. Perhaps the value of greatest importance to the consumer movement is that services should be voluntary. Some consumers maintain a steadfast opposition to any involuntary treatment, while others would like to see an involuntary treatment severely limited. Many consumers believe that if voluntary services and supports were more widely available and more consumer friendly, then the need for involuntary services would be minimized. Systems also should realize that involuntary treatment, restraints, and seclusion are very traumatizing and impede recovery, according to the National Technical Assistance Center for Mental Health Planning (1999)." *Editors note: A popular saying among consumer/survivor organizations states, "If it isn't voluntary, it isn't treatment."*

- **"Cultural competency.** Mental health systems are increasingly trying to ensure that services take into account the many cultural differences among the people they serve. Some of the strategies for increasing cultural competence include holding focus groups, conducting outreach, hiring bilingual staff and hiring professional staff and peer specialists from diverse backgrounds (Rogers, 1994; Stuart & Delgado, 2000; and Lewis & Graham, 2000).
- **Privacy.** One feature that draws many people to peer-run programs is that they provide a means of seeking support without having to provide personal information. Mental health systems must track information for billing purposes and because providers change; however, a consumer-centered mental health system respects consumers' privacy and does not disclose any more information than is absolutely necessary.
- **Advocacy.** In order for a mental health system to meet consumers' needs, consumers must have an avenue for having their grievances addressed. A consumer-centered mental health system gives consumers access to advocates and allows them to file grievances without fear of later retribution (Egan, 1995; Mowbray & Moxley, 1997).
- **Strengths-based design.** Consumer-centered mental health services are tailored to the individual's strengths. Rather than setting standards that a consumer must achieve, services focus on allowing consumers to set their own goals and work at their own pace (Deegan, 1988).

> **Flexibility.** Consumers have a choice of services in a consumer-centered mental health system. For example, they can choose the type of housing that is appropriate for them and set their own work goals" (Overcoming Barriers, 2001).

The traditional "one size fits all" mentality does not work. Each person's needs are unique to that person and must be addressed individually. Treatment plans should largely be the result of peoples' understanding of their own needs. Certainly, professionals play a key role in helping a person to gain that insight, but they should never lose sight of the wants and needs of the individual. People who have been denied the right to make their own choices sometimes need assistance in learning, or relearning, how to make those choices. Inherent in the ability to make "good" choices is the possibility of making "bad" ones. We learn through our mistakes just as we learn through our successes. With choices come goals, personal goals, not cookie cutter statements like "the client will work towards maintaining stability and medication compliance." Services centered on the individual work toward meaningful outcomes and promote empowerment and success.

Tools for Determining Success

Designing Evaluative Techniques for a Consumer-Centered System

Outcome measures for a recovery-based service system are not the same as for traditional mental health programs because recovery-oriented services are based on rehabilitation principles and focus on improving the overall quality of life. The use of person-centered survey tools such as the Personal Outcome Measures program, developed by the Council on Quality and Leadership, help to look at a person's quality of life by examining indicators, including these:

- Do people choose their own goals?
- Do they choose their living arrangements?
- Do they choose where they work?
- Are people satisfied with their life situation?
- Do they live in integrated environments?
- Do they perform different social roles?

- Person-centered decision making and choice
- Validated personhood
- Self-care and wellness
- Basic life resources
- Meaningful activities and roles
- Peer advocacy
- Staff treatment knowledge
- Access

“The ROSI bridges the gap between the principles of recovery and self-help, choice, hope, purpose, relationships, self-determination, empowerment, citizenship, resources, opportunities—and the real world application of these principles in the everyday work of staff and service system” (Onken, 2004).

Self-Directed Care

A Model for a Consumer-Centered System

One very innovative model has emerged in the Florida mental health service system, Florida Self-Directed Care Program (FloridaSDC). SDC was originally developed by a dedicated group of consumers, family member, and advocates. SDC epitomizes the concept of consumer-centered services. It provides an opportunity for individuals who have been diagnosed with a severe and persistent mental illness to assess their own needs, determine how and by whom those needs should be met, and manage the funds to purchase those services. In SDC, the funds follow the person. The FloridaSDC Program hinges on the belief that individuals are capable full participation of consumers in the planning and design of the services offered. People receiving services should be represented throughout the system. They should serve on boards of directors; be employed by service providers; serve in an advisory capacity to funding agencies and be employed by them to represent consumer interests; and run peer-operated services such as drop-in centers, employment services, respite facilities, and a full range of other services. Consumers should participate in training provider staff members, law enforcement agencies, and others. They should assist in the evaluation and monitoring of the system and provider agencies. It should be a consumer-centered system in every aspect.

Stories of Survival & Recovery

Spiritual Paths

Gordon Magill, *is a man of many talents. For many years, he has worked in several capacities, often with the central theme of helping others working toward recovery. In helping others, he has learned to find meaning and self-respect in his own life.*

He identifies many of the same elements in his story as the other storytellers have, but he also speaks eloquently of hope, respect, trust, choice, and, above all, his faith. Without these intangible qualities, it is difficult for anyone to find joy and optimism in their lives.

A Solitary Journey into Community

A toddler lies on the floor beside his bed feeling so weak that he fades into his surroundings. A kindergartner hides in a tent while friends engage in pretend battles. An elementary student tells his younger uncle that he would commit suicide today if he knew he would go to heaven. A middle-school child spends his evenings vomiting and crying from migraine headaches. A varsity wrestler is thrown to the mat and then watches from above as his opponent takes control on top of him. A high school student takes a personality test and is chagrined but not surprised that it labels him an extreme introvert.

This is my story but not my whole story. I attended family picnics, played with neighbors, and enjoyed competing in sports. I loved attending Boy Scouts, church activities, and summer camp. I proudly wore my high school jacket sporting my letter for wrestling. This is my story, too, but even in moments of fun, achievement, or activity, sadness, alienation, and fear were always nearby. This was especially true at night when recurring dreams invaded my sleep, jarring me awake sweating, trembling, and screaming. My childhood was a portent of my fight with mental illness.

I first saw a psychiatrist while I was in the Air Force. I wanted to be a man who was part of something proud and honorable. However, this was the Vietnam War era, and morale was low even among career enlistees. Worst of all, I was still me. Nothing had changed, so I smoked marijuana to "free my inhibitions" and "connect with others." This did not work; therefore, I dropped a tab of acid. I saw myself as a little gypsy boy and watched my heart explode. For the next month, the walls looked shiny and plastic, and everyone and everything seemed distant. When the world returned to normal, I fled to an old refuge, drank a bottle of liquor, and swallowed a bottle of Darvon. My roommate, a medic, found me with my "tongue down my throat turning blue" and revived me. Months later, I drank another bottle of liquor and took a bottle of aspirin. This time, I reported myself to my captain, who sent me to a medical doctor, who then sent me to the base psychiatrist. He invited me to a group session, where he sat with his tie flipped over his shoulder and a smirk on his face. This struck me as strange, and the conversation was even stranger. I returned to the medical doctor for weekly sessions. One day I told him about a family crisis that occurred before my suicide attempt. He then diagnosed me with situational depression, instructed me to keep busy, and discharged me from treatment.

I stopped all illegal drug use, took a part-time job in a children's hospital, and spent my free time at the base gym. When I received an honorable discharge, I took a job as a laboratory technician for the state of Ohio. For 2 years, I worked 40 hours per week, completed a second year of college, purchased and remodeled a house, raised old English Sheepdogs, and spent my free time at the YMCA. However, the desire to change persisted. This time, I looked to the faith I learned as a child, read the Bible and prayed: "Jesus, if you are real, if you are who you say you are, if you can do what you say you can do, please help me, as I have made a mess out of my life and I cannot help myself." Three months later, I believed in Jesus and He changed my life. I felt free and confident and stopped drinking. Nine months later, I entered the Salvation Army School for Officer's Training. Two years later, I graduated Magna Cum Laude and was ordained by Commissioning as an Officer in the Salvation Army. The college student who could not read a 5-minute speech without trembling and stuttering now spoke publicly on a daily basis. The laboratory technician who avoided people now performed the duties of a pastor and executive director of a religious charitable organization. But sadness, isolation, and fear invaded my new-found freedom and confidence, and now it was intensified by guilt about not reflecting the love, hope, joy, and peace of God.

The shadows of my childhood darkened and lengthened. I continued to suffer from migraine headaches. They were not as severe or frequent, but they still debilitated me, leaving me drained and exhausted the next day. Every winter, I experienced periods of sickness, sadness, and physical exhaustion. At social events, as others laughed and talked, I felt distant and alone. I was unable to handle conflict, and hard work brought growth, which brought conflict.

Major conflict erupted between me and the Corps lay leadership in my ninth year as a Corps Officer. I told my superiors that I needed help, and they transferred me to a different Corps in a different state. I worked harder than ever. My day began with early-morning breakfast meetings and ended with evening church meetings. Saturdays were spent at special events, and Sunday meetings lasted all day. I founded a Women's and Family Shelter, Homeless Day Shelter, Preschool program, and After-School program. I expanded the correctional services, direct services, and children's troop activities. Conflict reached a crescendo. Divisional leadership changed, and my new superiors wanted me to scale back on the social programs. The community members of the shelter committee resigned over our spiritual emphasis. A group of homeless people publicly protested shelter policies. The mayor of the city, who was up for re-election, jokingly asked me why I was taking all of his press time. Hard work and the success that it brings had now become the problem.

One day, while driving to work, panic assaulted me. My heart raced. I broke out in a sweat. Unfocused fear enveloped me. I started missing work and spent whole days in bed hiding under the covers. I asked for help, and a pastoral counselor diagnosed me with depression due to clergy burnout. My medical doctor prescribed an antidepressant, which increased my sadness and tiredness (I have never understood how a medicine that makes you sad and tired helps with depression). My superiors again transferred me to a different Corps in a different state, and I became worse. For the first time in my Christian life, I contemplated suicide. Faith in Jesus Christ stopped me from drinking and acting on my thoughts, but life stopped. My heart breaks when I remember my three sons coming to my bedroom, giving me their stuffed animals, and saying, “Get better, daddy.” But I didn’t get better. I stayed up all night listening to news about the Gulf War. One night, a sound startled me, and I rushed upstairs terrified that someone was hurting my boys. This prompted me to re-enter counseling.

I found it difficult to talk to the counselor. I wanted to talk, but I was buried under a mountain of silence. I gulped Excedrin and coffee before the sessions, so that I could at least respond to his questions. The counselor urged me to admit myself to a psychiatric hospital. Memories of New York’s Rockland State Hospital flashed in my mind. I visited this hospital with a group of Salvation Army Cadets in 1973.

diagnosed me as suffering from major recurrent depression and posttraumatic stress disorder and presented me a treatment plan. Their observations and plan were painful to hear, but I knew they understood me and my illness. I agreed to the treatment plan and began to attend the group sessions.

I hated group therapy; I hated the silly games. I hated the ridiculous comments on my childish art. I hated talking about my family, my emotions, and my problems. I hated listening to the other patients “wallow in their own misery.” I hated the regular bed checks with creaking doors and blinding flashlights. I hated signing myself in and out when I took a walk. I feared the psychiatrist. I don’t think it is necessary to say how I felt about the 12-step meetings. I did not want to resist, but initially I did not participate. However, I did enjoy the ropes course; the daily walks on the beautiful wooded grounds, and the tranquility of the meeting house on the lake. When I did talk and the staff confronted me, commended me, or gave me a new perspective, they were right on target. They understood me and they knew how to help me.

Six weeks into my hospitalization, I decided to open up to my primary therapist. Shortly after this, I recovered memories of childhood trauma. The terror of my recurring childhood dreams invaded my day, attacking me whenever I lay down.

4 years I did little recovery work. I realized I was stagnating, and I started seeing a psychiatrist again. He prescribed different combinations of antidepressants, but either they did not work or the side effects were not acceptable. He prescribed an atypical antipsychotic, which made me feel so drowsy and disoriented that after one pill I threw the bottle away. He offered to prescribe Xanax (alprazolam), and I declined at least 3 times, referring to my history of substance abuse. Eventually, I said yes and one evening my anxiety was so high that I took a double dose. That did not help, so I took another double dose. Then I took the remainder of the bottle, and all I remember thinking is, “I will either feel better or I will die.” My wife and middle son found me passed out on the floor beside the pill bottle. I woke up in the hospital and learned my stomach had been pumped, and then I was Baker Acted. A policeman drove me from the hospital to the crisis stabilization unit. He escorted me while I was donning an opened-back hospital gown, through the hospital to his cruiser. The officer treated me with respect and made conversation, but the humiliation of this moment was eclipsed only by my experience on the crisis stabilization unit. I felt like an object, not like a person. I received no treatment. The staff spoke to me only when they called me to meals. People sat in chairs staring into space or watching TV. The surroundings were stark and prisonlike. The next morning, two men interviewed me and asked where I got the Xanax. I told them and they said they would check out my story. One of the men asked me if I wanted to stay on the unit or go home, and that was the easiest decision I had ever made.

The condition of my “discharge” was that I see a psychiatrist and attend a follow-up meeting at the Community Mental Health Center. A peer specialist spoke of her struggles with schizophrenia and of her recovery. Listening to her experiences reminded me that where there is life, there is hope. When I saw my psychiatrist, he said that he did not remember prescribing me Xanax. I replied that I had the prescription bottle, and he flipped through his notes and said, “Oh, yes, I see it now.” I transferred to a psychiatrist from the Veteran’s Administration. He listened to me, and his response was caring and pointed. Finally, after more than a decade of treatment, someone actually prescribed the recommended antidepressant for people who suffer from posttraumatic stress disorder, and it helped, with minimal side effects.

I renewed my job search but met the same old silence and rejection, until I read a newspaper ad for a peer specialist on a Florida Assertive Community Treatment needed medication because work had become the best medication. is could not

mental illness had kept me from ever working or developing social relationships?

The answer does not matter for me. What matters for me is that I cope with the symptoms of mental illness and enjoy a full, meaningful life. The answer does matter for people whose lives are now being dominated and defined by mental illness.

Gordon Magill

Sally Clay *is the spiritual mother of the Florida consumer/survivor movement and a national leader in the fight for quality mental health services for people with psychiatric disabilities. As with all of us, Sally has worked for many years to overcome the barriers to living a full and satisfying life as she deals with her own illness. And, in that task, she has discovered her own*

In 6 years of marriage, I was hospitalized nearly as many times. The last time was a nearly 2-year stay in the Institute of Living (IOL), a long-term private mental institution. Before I left there, I had 30 shock treatments, and when those did not work, I made a nearly successful suicide attempt. Finally I was released from the IOL, but my marriage was destroyed, and in the divorce trial I lost custody of my really a psychological system. The books that I read precisely addressed the altered states of consciousness that I had experienced both in madness and in prayer. This was, literally, a revelation.

I had always known that there was an essential connection between my madness and spirituality, but I had never found a way to put the two together in a constructive way, with the possible exception of my prayer experience at the IOL. The next months were a roller-coaster ride that was alternately joyful and dangerous. As I visited the meditation center and then a Tibetan monastery, spiritual discoveries came with breathtaking clarity, but I had to deal with flights of madness that arose alongside them. At one visit to a Karma Triyana Dharmachakra monastery, I became manic one evening when the lamas and other staff members were out to dinner at a local residence. Filled with spiritual passion, I became annoyed with the other lay visitors who were laughing and joking in the reception hall. I got it into my head that they were desecrating the monastery, and impulsively I ran into the dining room and pulled down the lever to the fire alarm on the wall. The effect was instantaneous. A loud bell sounded throughout the building, and in the kitchen a poisonous white substance was released from the ceiling, covering every surface with a sticky white powder.

I was as stunned by this as was everybody else, and I quickly retreated to my room on the third floor, where I pulled out my bodhi seed rosary and started saying mantras. That is where I stayed all night, awake, not knowing when the lamas were coming home and what they would do with me. Early the next morning, a nun who was staying there came up to talk with me at the request of the lamas. She was gentle and kind, and very sympathetic, but in the end she was asking me to leave. I could only panic. I was in no condition to drive the several hundred miles that it would take to get home, so I refused to go.

A little later, the police arrived and arrested me for trespassing. They said they would have to take me to the judge in town, and as they escorted me to the police car, we were joined by the nun and two of the lamas, who followed us to court and sat with me while we waited for the judge. When the judge arrived, I pled “guilty,” and he sentenced me to jail for a week. I served my time in an unusual solitary cell that had piped-in rock music. When released from jail after this experience, my mind was in total confusion and I had nowhere to go. Somehow I made my way to a motel, where I stayed for several days, and drank bottles of wine that I had delivered to my room. Eventually, when I could not pay my bill, the motel manager had me picked up and committed to the state mental institution in the next county. I was held there for several weeks, over Christmas and New Year’s, in conditions so hellish and dismal that I was obliged to get my head together just to get away from there.

Finally, I was able to drive all the way home to my single apartment in the city. It was time for another fresh start. This time, I got a new job at a radio station, and, remembering all the wine I had drunk in the motel, I joined Alcoholics Anonymous (AA). I decided to make AA my spiritual path, and I also returned to church and joined another choir. At this point, I assumed that I had worn out my welcome with the Buddhists.

I attended AA regularly and benefited greatly from the various types of meetings and sponsorship that introduced me to the value of peer support. However, after a year of being clean and sober, I broke down again. Clearly, eliminating alcohol was something I could easily do, but I was still powerless over madness. Now I even lost cry for mental health consumers around the world. It was a genuine movement that held implications for healing the whole world. And as any good bipolar person will tell you, saving the world is what it's all about.

There was just one problem. Even after advocating helping myself and others for several years, I was still going through destructive manic episodes. I was still being picked psychotic out of the shambles of my living room by the police and dumped into jail or the state hospital on a yearly basis. It could not go on like this. I decided that it was time to return to the monastery.

When I sheepishly returned to Karma Triyana Dharmachakra, I was genuinely surprised to find that my lama even remembered me. Not only that, he chided me for not letting him know how I was and what I had been doing! He was pleased when I described my advocacy, and he even smiled approvingly. I was touched and grateful. Later, in talking with some of the other students who knew about the chaos that I caused with the fire alarm, I learned that Rinpoche had watched what happened from the staff house and giggled.

After several weekend visits and more talks with my lama, I decided to move to the town near the monastery. This time, I applied myself to learning more about Dharma practice, about what the Buddhists call "mind training." Mind training is exactly the right term for Dharma practice, and my first impression of Buddhism as a psychological system turned out to be accurate. The liturgies and prayers that I did at the monastery were a demanding discipline that involved effort as well as devotion. There were times when I regarded the prayer ceremonies as a kind of mental calisthenics. At other times, as I learned to experience altered states in a controlled fashion, I could sense that something was actually happening in my physical body and especially in my brain pathways. Sometimes these were pleasant sensations, but at other times it was a bit painful to deal with mental states as they arose.

The end result was that I noticed gradual, almost imperceptible, improvements in my attitude and my behavior. I could see that other people instinctively trusted me more, and I experienced much less fear and anger. It was easier to maintain my confidence and composure in dealing with situations that had previously been stressful. I continued these habits of daily prayer even after I spent less time at the monastery and returned to doing mental health work. It occurred to me that the work with my peers was a sort of training in compassion, while the prayers and Dharma practices allowed me to develop wisdom without the loss of grounding that can lead to madness.

All of this, of course, was a process that only started during my time at the monastery and had to be maintained. During a couple of years when I lived in another state, I neglected the spiritual disciplines that I had learned, and that led to another brief manic episode. Nevertheless, except for that one embarrassing slip-up, I no longer have the annual breakdowns that I had with such regularity before I started Dharma practice. As I write this, it has been 20 years since I started mind training, and I have succumbed to madness only that one time in all those years.

Grant your blessings that my mind may be one with the dharma.
Grant your blessings so that dharma may progress along the path.
Grant your blessings so that the path may clarify confusion.
Grant your blessings so that confusion may dawn as wisdom.
~ The Four Dharmas of Gampopa~
Sally Clay

Gina Basile attributes her recovery to excellent treatment, her work as an advocate and facilitator, and, above all, to her spiritual beliefs. Gina works as a consumer recovery manager for a Medicaid managed care company and feels blessed in her opportunities to help others.

My Spiritual Path to Recovery

My name is Gina Basile, and I am currently living in Miami, Florida. This is the story of my spiritual path to recovery. I was born in Colon, Panama, Central America. I have been living in the United States since 1988. I was diagnosed with bipolar depression in August 1998. I was hospitalized 7 times before my recovery began. I had no private insurance, but I was fortunate to be hospitalized in excellent public institutions. My life before the illness was fast, wild, and unstable. I started to have symptoms in my late 20s. During college, I had two or three jobs, and I had a crazy love life. Some people may have seen my college life as an adventure and fun life, but in reality, it was the beginning of my calling from God. I believe that all of us have a calling and a purpose with God. Thanks to my illness, I've gotten closer to God. My relationship with Christ has become my tool to recovery.

I had just graduated from college in 1995 when I had my first episode. I was working for the Career Planning and Placement Office at Florida International University. I had clinical depression with psychotic symptoms. I heard voices and had hallucinations. I started to harass and assault my boss at the university. I thought that my boss was my mother and that people were following me and talking bad about me. I lived at home during this crisis, and I still live at home due to changes in my career because of my illness. My recovery was slow but steady. In 1998, when my mind flipped and I became psychotic, I realized that I had to make drastic changes in my life; if not I was not going to recover. My personality is and was hypomanic. I am glad that I suffer more from highs than lows.

My recovery was definitely a spiritual recovery. During my last hospitalization, I asked God to give me an answer. I didn't want to take medications, but thanks to God there was a Christian believer in the cafeteria who talked to me about God and told me that I needed to take medications to recover from my illness. My life started to take a different direction and perspective; I became aware of my emptiness and rage at life, myself, and my family. I realized that mental illness is an illness from the heart, mind, and soul. I found my brain's reaction to the medication and to God's healing fascinating and intriguing. I believe in the power of God due to my recovery and luck in life. I know of consumers who have taken medications for more than 10 years and have not recovered because they haven't found God in their hearts. I am currently taking medication. I am only taking

Geodon (ziprasidone) and Wellbutrin (bupropion); because of my progress, my doctor suspended the lithium in my plan. This same doctor had told me that I needed to take lithium for the rest of my life, and, to his surprise and to God's glory, I have not been taking lithium for more than 2 months and I feel great. Seven years have passed since my last hospitalization, and God is doing wonders in my life. Of course, I attend support groups, control my sleeping habits, have

provides access to other services as the individual chooses. Individuals entering into the program are offered immediate access to permanent, independent apartments of their own (Tsemberis & Eisenberg, 2000).

In Orlando, the Pathways Drop-In Center has created its own supportive housing program. After many years of struggling with landlord issues and repairs, the center was able to obtain grand funding to purchase their building. Along with the drop-in center, Pathways acquired 7 apartments which it has made available to members as part of the project.

In the words of Nelson Kull, President of Pathways,

> When it was over we owned the property and it will probably be a community asset for many years, if not generations. We pledged in the grant to keep the rent down to 33% of an SSI check. So our members pay $200 a month in rent, which includes utilities. Everyone goes to sleep behind a locked door that only they have a key to. Everyone has their own TV. Everybody has a computer with a broadband Internet connection.
>
> The reason they have these things is because average Americans have these things. Pathways' philosophy is that people with mental illnesses should have the same things that other Americans have.
>
> There are seven units. Some share kitchens and other space. Couples have to share a bedroom and pay $300. Couples do not have to be legally married because it is none of our business and because couples on SSI normally do not get married because their benefits would be cut due to a marriage penalty. Also, gay couples are treated the same as others.

Peer supports and peer-run supportive housing programs offer substantial advantages to consumers in terms of knowledge of their needs, respect, empowerment, and their willingness and ability to break down traditional boundaries. Housing represents another area in which peer-run services can excel.

Stories of Survival & Recovery

Lives Interrupted and Reclaimed

Clint Rayner, *has lived an extraordinary life. He has gone from growing up on a small southern farm to corporate heights, from mental patient to consumer leader. Clint is a survivor.*

He speaks passionately about the power of helping yourself by helping others and the importance of preserving your sense of self-worth, your self-esteem. Believing in himself and that no problem is too big to solve has carried him through in times of illness and despair. He credits compassionate therapy, effective medications, a supportive network of peers, and the love of family and friends for aiding in his recovery. Clint's story, ***From Patient to Advocate****, is an inspiration for us all.*

"No big step for a stepper." That's what my father used to say when I was growing up on a farm in Mississippi. A stepper was a person who could keep up with the mule no matter how fast it plowed; it was just a matter of adjusting one's stride to match the unpredictable mule's. For a child, however, this was a challenging task, so if an adult called you a stepper, it was a compliment; it meant no problem was too big for you to handle.

even stronger on that road. I developed three mantras that began to shape my foundation of knowledge and enlightenment toward becoming actively involved in the cultural change of recovery and resiliency. I developed my own version of active movement forward through an application I call Visualization, Verbalization, and Actualization. This process of perceiving life's goals in your mind, of sharing this vision of dreams, and finally placing into action the pursuit of those dreams, allowed me to overcome and surmount many of my personal and societal barriers.

One of the paid jobs that opened many doors for me was serving as a consultant to the district office of the Health and Rehabilitation Services, which later became the Department of Children and Families. One of the projects with which I consulted with the department was the training of new social workers, in which I co-trained with a staff member of the state agency. During this time, I wrote Threads That Connect: One Persons Approach on How to Deal with Mental Illness. This simple statement of belief, acceptance of responsibility, and the understanding of the importance of HOPE, was published and has touched hundreds of lives. I have put it at the end of this story as a humble gift in the hope that it will bring some comfort to someone reading this story.

I eventually moved into paid positions with Lakeview Center as a psychiatric technician, trainer, and I became the first patient advocate at West Florida Community Care Center, the same hospital where, 2 years before, I had been a patient myself. I had come full circle in another way as well: on my path to discovery, I found my calling and became the first advocacy coordinator with Lakeview's Access Behavioral Health, the managed care division of Lakeview Center. In addition, in my 15 years as a full-time employee, I served as a volunteer on the boards of numerous organizations and was appointed by Governor Bush to two state advocacy councils primarily responsible for protecting the rights of individuals with disabilities. I also became the Chairman of the PAIMI Advisory Council of the Advocacy Center for Persons with Disabilities, the federally mandated organization to assure that states meet federal statutes. I was fortunate to become a founding member and officer of the Florida Peer Network, the state's first consumer organized and operated organization. **"No big step for a stepper."**

When, in early 2006, the Governor's Office created the Office of Consumer and Family Affairs (OCFA), within the Department of Children and Families' Mental Health Program Office, it assumed primary responsibility for the transformation of the mental health system in the state of Florida. Fifty-six people from across the nation applied for the position of OCFA director, but, from the outset of the search process, this boy from Mississippi, who had successfully adjusted his stride to match that of the unpredictable mule, went through a rigorous process of application and interviews to become Florida's first Chief of Consumer and Family Affairs.

In this case, the mule was mental illness. In manic cycles, bipolar disorder had swept me up behind the plow at breakneck speeds, and in depressive cycles my feet were barely able to touch the ground. I felt as though I were the mule, dragging the plow through the sucking muck and mire of an existence I wanted only to be rid of. With the help of compassionate therapists, the right medications, and a

only tools, which I may or may not choose to use. It is not their job to make my life better, it is my job and I must accept full responsibility.

I believe that hope and understanding go hand in hand and it is these two hands that will pull me from the depths of mental illness and will give me the courage to face the sunshine. I am not ashamed that I am mentally ill, I am not afraid of what the future brings. I believe that hope is the art of patience and I am willing to wait. It is better to understand just a little bit than to misunderstand a lot. With this fear removed and understanding accepted I now free myself to become once and for all a dreamer.

I will not quit.

I owe my life to myself because I have endured it, to my brothers and sisters who went before me because they suffered it, and finally to the children who follow me because my ability to overcome this illness will become my legacy.

MY LIFE DOES COUNT, Clint Rayner, Copyrigl7ept fullsteED [(MY LIFE DTm [(only 20.1371l48

A psychiatric assessment center helped me find a source of medication again. The center also ran a day treatment program. Despite my doubts after my last day treatment, I ended up going there. And even to this day, I miss it. It was the best.

This program was great because it was long term (I stayed from July 1998 to February 1999) and because the people were really caring. I had a car and could drive myself, but the occupational therapist always said to me, “We’ll pick you up.” This was so helpful because I had to be up, showered, and ready for the car at 8:30. It got me out of bed.

Volunteering was another major part of my recovery. I was able to secure a position volunteering for 3 years at Broward Housing Solutions, as a result of attending the day treatment program. Now I work there part time. I help people with mental illness find housing, which is something I want to do. It’s a far cry from the other jobs I’ve had. I never thought I’d be paid to talk on the phone! When I first started volunteering, it gave me great pleasure to leave the house for a couple of days a week to organize and file paperwork. Giving housing referrals is one thing, but when one of the customers moves in they are elated. The agency also helps with living expenses. Housing fills a basic need that we all have, just like food. It provides a place you can

apparent long before she and my father divorced, showed up dramatically when she was raising us children. Once, when I was 3 years old, she tied me up in ice-cold wet sheets to punish me for saying, “NO!” Another time, she punished me by tying a rope around my ankle and attaching it to the stake we used to keep our leashed dog from running away.

Living with my mother again crushed me deeper into despair, but I had no place else to go. My personality had lost all will to go on. I felt transparent, flimsy, and tired, without the strength to undo the situation I had created for myself.

Once again, my mother abandoned me.

After being sent to live in an ultra-religious commune, I met two women who had earlier known my grandparents and who knew of my mother’s illness. They got wind of my plight and pulled me out of the quagmire. These heroic women did not know me personally, but they were compelled to drive to the mountain home of the cult to rescue me. They made a few phone calls, and, just like that, I had my own efficiency apartment and a new job in a hospital in Denver. I felt momentary relief, but I was faking functionality just to get through the next minute. I didn’t feel gratitude. I didn’t feel much of anything.

For a few weeks, I got by. I worked in a pharmacy inside of a hospital. I was subdued for the most part, just shuffling along, working 3 consecutive days for 12 hours a day, followed by 2 days off. Like a robot, I stuck to my schedule. Every time I was not at work, I slept, ate, and watched TV in my pajamas.

I was alone. Nobody called, nobody wrote. Somewhere inside my sick mind, I decided to bring the misery to a halt. I could not pull myself out of my dilemma. I could not do simple tasks well. In addition, I hated myself because I saw the failure that I had become. It was clear to me that the only way out was to die.

I woke up. I was lying on my back, squinting at the glaring lights above my bed. The smell of vomit was in my nostrils. My stomach, pumped from the poison, allowed me to escape my plans for death. Having been unconscious for about 5 hours, I sat in my wheelchair as an attendant carted me away from the emergency room, aware of yet another unfortunate failure.

I had quietly planned my exit at work as I breezed around the hospital on my little pharmacy cart. I felt certain there was some medication in the pharmacy that could help me die quickly and easily. It was not hard to take home a bottle of phenobarbital. I was not crying for help. I was certain of this decision.

I swallowed the entire bottle. As I became drowsy, I said a prayer of thanks to my guardian angel, telling her how sorry I was for failing her, for failing at being alive. Then, I fell deeply into sleep and would have been successful if my boss at the pharmacy had not interfered. Since I had not shown up for work on time, the pharmacy office assistant called me. She heard a garbled sound as my phone dropped to the floor, and since subsequent calls were answered with a busy signal, my boss told the security guard at my apartment complex to check on me.

The hospital transferred me to a local sanitarium. It was the autumn of 1977. The sanitarium’s gardens were shimmering with falling yellow aspen leaves. I was feeling

months, despite my seeing my new doctor regularly, I used up cartons of Kleenex, dabbing the runny tears that accompany depression.

The desire to die came thundering back from its hiding place in the depressed folds of my brain. I woke up thinking about how to go to sleep permanently. Since I had no access to drugs and I was too sluggish to attempt a drowning, I sat trapped in my misery.

I went off my medications in early summer 2003. It wasn't until June 2005 that my chemistry became balanced again. My decision to manage my disease without a doctor and without medications cost me 30 months of life, with a hospital bill of more than $30,000 plus massive credit card debt due to the temporary inability to make a living. This tally does not include the upset caused to my family and my clients.

Editor's Note: Daina has successfully been pursuing her recovery for the past 2 years. The following interview reflects her thoughts on the nature of recovery and how she maintains it.

How do you know that your chemistry is now balanced, after so many traumas?

I am a grateful, happy person. I enjoy creative work and sustaining my relationships, most of the time. I perceive myself as reliable, diligent, capable, delightful, caring, and funny. I am who I am again.

You speak of "transition." What does "transition" mean?

I am bipolar. The medicine has restored a high measure of balanced brain chemistry. My recovery is mostly about realizing a way of living that is not let go of by guilt, resentment, and judgment. My recuperation is about more than my disease. I am making progress in the art of being alive.

What do you do when doubts occur?

Sometimes I let doubts take over. Within a few minutes, I can create a wide range of misery, for myself, and those around me. The instant I pull myself back from the drama, I find peace. Pulling back from my pity party takes work.

I have my own vocabulary, rituals, and techniques for returning to peace when I stray into self-centered fears. It is easy to find stillness just by concentrating for a few moments on normal respiration. While I am aware of my breath, as it flows in and out of my body, I am unable to worry about the past, or to feel any embarrassment for how I've acted due to bipolar episodes. Gentle concentration also screens out concerns for the future. For a little while, I am alive in the "now moment," refreshed and ready to continue my day.

What is your mood like on most days?

My doctor says that I am now balanced. My brain chemistry receives medication every day so that it can function as if it were normal. I feel a range of emotions but am capable of choosing how I respond in any situation. With medication and spiritual discipline, I can focus. I finish what I start. I feel happiness. I feel loved.

What have you learned from your experience?

I am grateful for the wisdom that my disorder has brought into my life. I am now able to share hard-won insight. I am grateful to live in an era where I don't have to die from the symptoms of my disease.

I respect that my brain was born with a lethal condition. I take my condition seriously. I have sought out and found friendships with people who respect their bipolar diagnoses, and who encourage me to stay on the path of mental health. I take my medicines without resistance. I know that I can realize my dreams because I can trust my brain chemistry to work well. I recognize that I am a person of value. I allow my life to take new and different paths, not asking the future to look just like my past.

Daina Gold

Janice Eberly Anastasato is the director of one of the most innovative peer-run services in the country, the 9Muses Art Center, a drop-in center for the arts. Jan has helped to develop a wide range of progressive consumer-centered, peer-run services in Broward County, Florida. She names peer support groups, wellness education, giving back through meaningful work and acceptance of her illness and its treatment as being fundamental to her recovery.

I was born in Los Angeles. My parents divorced when I was 5, my mother remarrying a soldier during World War II who was abusive to her and had threatened to kill me if she didn't. We moved to his family house in West Virginia when I was 9. My father had also remarried and, after being discharged from the Navy, became a Los Angeles motorcycle cop, fathering 5 more children. Mother's second husband had been classified as paranoid schizophrenic by the army, but they kept him on active duty anyway. After the war, he returned to West Virginia. spending his days drinking and terrorizing the neighborhood with his hunting knife and gun while my mother worked to support us. He was a tormented soul who would not go for help. Two years later, while he was beating me, she shot and killed him. Residents she didn't know called the authorities to support her. She was not arrested, and no charges were filed. I was 11 and it was Easter Sunday. I just remember neighbors out in the street gawking at the house and my having to show my bottom to the state police.

Mother married a third time when I was 15 to a man who was very good to both of us. I finished high school in Charleston while dancing with a ballet company, went 1 year to the local college, and then transferred to Florida State University. College away from home helped me overcome my shyness and grow socially. I graduated with a BA in French.

After graduating from FSU, I went to work for TWA in Pittsburgh, moving to its Atlanta office after 1 year. I met my husband, Pano, who was with Alitalia Airlines there. He was promoted and summoned to New York while I stayed in Atlanta for the birth of our son and then went to see my parents in West Virginia until Pano found us an apartment in New York. We lived there for 9 years. Pano left Alitalia after the first year in New York City, starting his own business as a wholesaler

Pano chartered a plane, flew my mother, my “boyfriend,” himself, and me to Athens, where the boyfriend’s wife, having flown in from Puerto Rico, waited, so that was the end of me and my boyfriend. I don’t know how all these people got notified to come to Athens! The three of us went to a downtown hotel, where I escaped to a restaurant next door and sat with some local movie people, who shared their wine with me.

Soon after, like a B movie, two men in white coats came in to get me and took me in their paddy wagon to the emergency room of the nearest hospital, where I was given a shot of what they said was B12. My husband’s retired Greek general friend drove us under police escort to the Gallini Clinic in Kifissia, a suburb of Athens. I was sedated and struggled to keep my eyes open during the trip and the intake at the clinic. I argued that my husband had no right to commit me, but money talks and they admitted me. I spent 11 days there still in mania, trying to plot my escape. The first day, I was in restraints and was heavily sedated. It was the first time I was ever locked up, and I was terrified that I might be forever!

I was released to the care of my mother with a list of 11 recommended medications, almost all major tranquilizers. I was permitted to stop and see my mother-in-law on the way to the airport with two undercover detectives following to make sure I got on the plane, and stopped in Geneva to see my son before flying to Paris and Miami. My brother-in-law escorted us as far as Paris until we boarded the flight to Miami to make sure I didn’t try to escape.

I resumed my visits to the psychiatrist, who tried other medications. My insurance didn’t cover mental health. Pano spent a lot of money cleaning up my messes (like the outrageous Geneva hotel phone bill, plane tickets, clinic bill, detectives, doctors’ visits, etc.).

I worked some temporary jobs through Kelly Girls and Manpower, going from mania to depression with no periods of stability in between. My mother and I went to New York for a consultation with Dr. Fieve, who wrote the book Moodswings. He said to take lithium and go to AA. Most of the psychiatrists I saw insisted that I was self-medicating with alcohol; some even said I could drink in moderation. That may be true. I didn’t drink when depressed, only when manic to relax and try to sleep. However, it is probably more accurate to say I have co-occurring disorders, formerly called dual diagnosis. For a long time, I could not accept that I might have both a mental illness and a substance abuse problem.

Because no medications had worked up to that point, I joined AA for 3 years and 3 yp s myw were chewed down to the quick! Neither of us thought that he'd be of much help, nor were we impressed with a doctor in West Palm Beach who specialized in electroconvulsive shock therapy. He wanted to admit me and give me a series of 30 treatments! We both fled from that. I began going to another private psychiatrist, who looked like Freud and had the famous psychoanalyst's photo on his wall so that we could see the resemblance. I also saw a pastoral therapist with whom he worked. Therapy sessions seemed to be conducted in my manic or depressive state (diarrhea of the mouth or nothing to say), so I doubt I was getting anything out of them. Once again, I was going through trial and error on the meds and the doctors.

I was forced into the hospital for a month. I wasn't given any medication because my blood pressure was too low. I saw my doctor for 5 minutes every morning, and when I asked to go home and work on my problems there, he said, "Just stay in the hospital for a month like your husband wants." The significance didn't register with me at the time.

The psychiatrist went to Ohio to undergo heart surgery. When he returned to work 3 months later, I was in mania, and as he refreshed his memory about me by looking in my file, I saw a letter on top of the file to the Internal Revenue Service. He said that the IRS had wanted me to appear in court in New Rochelle, New York, to testify about our joint tax returns. He wrote back to the IRS, saying that I was in the hospital and was too sick to appear in court. Obviously, he was paid and not consulting with his patient was certainly a breach of ethics! Had I not been manic, I could have sued and probably won! I fired him.

In 1982, I worked for the Hilton and Ocean Manor Hotels on the beach in their sales office and was employed there when the New York Philharmonic with Zubin Mehta and his wife Nancy Kovack were guests, along with Rex Harrison and Claudette Colbert, who were appearing in a play at Parker Playhouse. I arranged for all of them to be the guests of Le Club International while I was still hypomanic. As I escalated into mania, it took only a couple of months before I was fired. After a year at a hotel on Pompano Beach, I worked as a night auditor for Pier 66. After 3½ years working nights, I went to work for a brokerage firm as a wire operator. At that time, brokerages gave employees health insurance after the first day of employment. I was at this job when I was diagnosed with breast cancer. I had a modified radical mastectomy and the following year began undergoing reconstruction. I mention this because each time I had anesthesia, it threw me into hypomania. In previous surgeries years before, I had the same reaction, but it wasn't recognized as mania. After 2 years, I moved to another brokerage firm, where I worked as a secretary. It paid better, but I hated it and the lack of ethics I saw there.

In 1987, Pano won his criminal case with the IRS but lost the civil. He filed for bankruptcy and moved to Greece. I had no more income from him.

My last big episode was after the last stage of breast reconstruction in 1991. I lost my job, housed 8 around-the-world Whitbread Race sailors for 3 weeks during the Fort Lauderdale stopover, and lived off of my credit cards, which led to bankruptcy when I crashed into the inevitable depression. The second psychiatrist I saw in this period prescribed the right medications for me, and I began to get better. In total, I have seen 11 psychiatrists, and only two or three did I consider good. I flew twice

Health (ADM) Planning Council. In 1993, I was one of six, two of us being primary consumers and two secondary board members for the startup of the Broward County Community Development Corporation (CDC) d/b/a Broward Housing Solutions. I think we were the first nonprofit to specialize in permanent, affordable housing exclusively for the mentally ill in Florida. We may still be the only one. Fourteen years later, I'm still on the board. For more information on the agency, please visit www.browardhousingsolutions.org.

Ten years ago, we took over the drop-in center, which started as Hot Sketch Studios in 1995, changed the name to 9Muses Art Center, and added a gallery and frame shop. I was put in charge of the program and still love what I'm doing! I had fun working for the airlines, but this job is rewarding and I feel as if I'm making a difference. We have more than 2300 members (once a member, always a member) with approximately 300 coming regularly. In addition, we have approximately 50 members who are not diagnosed and pay a fee to join, sitting in classes with our consumer members. This setup is sort of stigma in reverse, because they come in to join us and realize there's not much difference. Rather than go into detail about 9Muses, I suggest that you visit our Web site www.mhabroward.org, open the first paragraph for the home page, and find 9Muses in the left column.

Broward General Medical Center has purchased 44 paintings from 9Muses artists for its 3 psychiatric units. In 2005, 9Muses consumer art was used exclusively in the film, Canvas. The film is about a painter with schizophrenia and her husband and son. It should be in theaters by September 2007. Written and directed by Joe Greco based on his childhood, it stars Marcia Gay Harden (Oscar winner for Pollock) and Joe Pantoliano (Emmy winner for The Sopranos). You can find more info on www.canvasthefilm.com including a great review in Variety. GEOCare, who took over the South Florida State Hospital when it was privatized, has commissioned 28 4'x 4' plywood murals after receiving the eight 4'x 8' murals we

Supported Employment

Employment is an important ingredient of the complex mix of supports that helps a person to return to the community after institutionalization. It is one of the main ways we are connected to our social environments. It is where many people meet and make friends, participate in meaningful activities, and find respect and purpose in their lives. It is the path out of poverty for people used to living a minimally sustainable life. For many of us, it is a key part of our self-identity. All too often, people are "placed" in minimum-wage jobs that hold no satisfaction in their performance. "The focus must be on creating jobs with career potential rather than low-paying, dead-end jobs" (Rogers, 1990). These types of jobs have the added value of often providing health and retirement benefits to the employee who would otherwise be without such supports.

"Just as people with psychiatric disabilities are profoundly affected by trends in affordable housing, their fortunes rise and fall as the economy experiences varying levels of unemployment. Downward shifts in the labor market typically result in abysmally low employment levels among people with psychiatric disabilities" (Carling, 1995). Even during these downward shifts, many of our mental health and vocational rehabilitation agencies focus on providing entry-level jobs with little or no possibility for advancement. "For this reason, increasing numbers of consumers/ex-patients resist participation in such programs even though they may lack the proper resources and/or skills to secure employment on their own. It is unclear to what extent the very low success rate in employment for people with psychiatric disabilities is a function of unattractive programs and lack of real job options, rather than deficits in clients" (W.A. Anthony in Carling, 1995).

To make employment a viable option for people with disabilities, it is important to find ways to secure medical benefits after they return to work. Programs such as the Social Security Ticket to Work and the Work Incentives Improvement Act give states the option to provide Medicaid "by-in" programs to those who no longer qualify for benefits. Accurate information about a person's benefits and the risks involved are often critical parts of the decision to go back to work. It is also important that accurate information be available about the process for reapplying for benefits if working proves unsuccessful.

Supported employment finds it roots in the developmental disabilities system. According to Anthony and Blanch (1989), it differs from sheltered or transitional employment in that it stresses "(1) a goal of freely chosen paid employment for all people with disabilities; (2) integrated work settings; and (3) ongoing support,

but also for the aroma of fresh-cut grass and leaving a neat, weave pattern in the lush Michigan lawn. I got good grades in school, mostly A's but some B's.

Then one day my parents gave me some great news. We were moving to Gainesville, Florida. I was so excited. I wasn't a big fan of the snow, ice, and cold weather. I remember my Dad picking me up at the old Gainesville airport. My initial reaction was not too keen on Gainesville until we got to University Aveenue and 13th, and I saw the cornerstone, University of Florida. I knew I was home.

I made a lot of friends at Buchholz High School because of being in a band. I was the new kid on the block and a good trombone player by now. Later that fall, I challenged the first chair player and won. I was now first chair, and the band was 10 times better than my old high school band up north.

Things couldn't be going better for me. Now this is how the second part of my life all came about. It came in early June. My buddy and I went down to Melbourne for a band clinic. On the way back, he was driving my parents' compact Datsun and I had my seat fully reclined, sandals off, no seat belt, and sleeping. He fell asleep on I-95, going maybe 70 or 80 miles per hour, and we veered off into loose dirt on the shoulder of the highway. The wheel spun and flipped the car end over end approximately 4 times. We both walked away from it seemingly in good health. He had a bump on his head, but I was walking on the hot pavement, barefoot, with glass all over the place and didn't feel a thing. I had found a girlfriend, who was a freshmen, and I was going into my senior year. She, too, was an All-State player, but she was a true virtuoso on flute for her age. We hit it off so well, but I only started hanging with her when my illness started kicking in. I could tell that she had a crush on me and I liked her a lot, too, although I was a senior and she was a freshman. At that age, there is a big difference.

My parents were out of town, and when they got back, I was pretty much out of control with mania. I was taking risks while driving and doing other things. although I was looking so forward to my senior year.

On August 20, I was looking in the mirror, brushing my long hair vigorously, lots of static electricity, when my mom either knocked on my door or reopened it. I fell to the ground with a primal scream. My mom helped me as my dad and family wondered what had happened to me. I couldn't sleep, and I remember walking clear across the house in the dark to their room. My mom made me some tea and toast. My dad was working late hours at the bar, but they both got up to try to get me to sleep on the sofa in their parlor. When I still couldn't sleep, my dad got frustrated with me and we started fighting, and that's when my mom called 911.

The paramedics took me to the old Alachua General Hospital, Psychiatric Unit, which was on the 4th floor. It was a scene out of One Flew Over the Cuckoo's Nest: green walls, gra

perhaps not judged by your family, whom you'll devastate, but by God, who may not redeem you to Heaven. I don't see suicide as a cowardly act but, in most cases, a way out of pain that no one, absolutely no one, could understand. As St. John said, "it is a long dark night of the soul." You just can't snap out of it, as I've heard so many times during these times of crisis. I'm just grateful to God that care for the mentally ill with better facilities, doctors, and research for more effective medications is all coming together.

In my case, my manias were almost always filled with delusions. A favorite delusional character of mine is King David. I actually thought I was him and, therefore, the world should treat me like royalty. How can you top being King David? My delusion after that was that I was the Messiah. I acted as if the word revolved around me. This would take me to such great heights of grandiosity. You would never want to come down to live by mortal standards. I recall one hospitalization in Ft. Lauderdale when I tried starting a revolution with the other consumers from the psych ward. The doctor didn't think that was too good of an idea. Later when I was released, still quite hypomanic, I told a therapist this, and he replied, "Why don't you start a movement instead?" Well, that didn't have the same thrill to me in which I would be in control of this revolution. I gave up on the idea as the medications started working again.

Let me just say now that, for most of these past 30 years that I've lived in Gainesville, I can't speak more highly of how the Gainesville Police Department and the Alachua County Sheriff's Department have handled me in all of my manic moods. They've treated me with care and always got me to the hospital before I did something dangerous.

In all of my anger, the best advice I've ever gotten came from a monk. He was my parents' best friend in high school, but I've visited him at the monastery a few times. When I called him from the psych ward, angry as can be, his advice was, "Greg, you don't want to take that anger to the grave." On another call to him, I was so depressed. I was going to day treatment and told him I was tired of hanging around these people. His quote to me was, "Where do you think you would find Jesus if he were here today?"

What I've come to learn now, as I am growing in age and wisdom, is that anger and depression are such draining emotions. I realize they are necessary because we are human, but we are also spiritual beings, and I believe in a God who became man to experience these emotions. This is all I need to keep me going. This is my belief anyway.

On the corner of S.W. 4th Avenue and 10th Street in Gainesville now resides the parking lot of the Emergency Room of Shands at Alachua General Hospital, but many years ago, after tearing down the old 4th floor psych unit, they put up a temporary psych unit, which was a doublewide trailer.

My first visit to the trailer was after my hit-and-run car wreck in 1978, and I think my last visit was in 1986. During my first visit, I remember my dad staying right there in the room at night with me, he cared so much. I think the doctors and nurses persuaded him to leave me in their care. I just can't imagine the hell I've put my parents through for 30 years, but they love me more now than ever before; they just wanted the best care for me. I love them so much, too, for all their patience.

In this trailer, as in all psych units, was a glass observation room where the doctors and nurses would gather. I always thought most of the doctors were really cool, and they tried so hard to get me the right mix of medication. Although I had a lot of rough times at that trailer, I thank God for the improvement from my fi

I love the swimming pool. I try to do 50 laps every other day or so. I can feel my arms tightening. I also ride my exercise bike 50 minutes on the days that I don't swim. Some days, I'll even do both.

I am writing this page on June 3, 2006, and I have the whole summer to do all these wonderful activities. This is what I mean when I say persons with bipolar disorder can be very creative and productive when stabilized. I still get about 8 to 9 hours of sleep every night, but now that I'm on vacation, sometimes I'll get up in the middle of the night and either take a dip in the pool, listen to smooth jazz on the radio, write, or work on my music.

I'd like to tell you about two individuals (although there are others) who have been so patient with me and have seen me through many highs and lows. The first person is my mental health nurse, who counseled me from 1978 to 1986. She was so kind and patient with me. She had the patience of a saint because I know that people in her profession are compensated poorly, and it is easy for them to burn out. I thank her so much for those tender moments when my life was on the line and she knew just what to do.

The second long-term therapist I've had was a licensed mental health counselor. Just last Friday, I graduated from him because I am getting proper care from a really great therapist on my FACT Team. I've been seeing this therapist since 1995. For 11 years, he has been a rock. Actually, he always described me as a tightrope walker, and there is a safety net below me with posts and mesh. This was my network system made up of people who can help me from crashing to the ground should I fall. He describes the posts as my parents, the FACT Team, my family, and himself. The mesh would be made up of friends or the Crisis Line.

I'd like to conclude this story by mentioning some other people critical in my healing process. First of all, only two nurses have known me since Day 1 at the old Alachua General Hospital psych ward. One of these nurses still works at Vista Pavilion, where I only see her when I'm hospitalized.

The other became a professor of nursing, and I see her many Tuesdays when she accompanies her student nurses. She was always so cute and perky. When we were reunited at FACT, I was still hypomanic, so I said to her, "You got old." She laughed and said, "You sure have a way of influencing friends." We laugh about that now, but she still is the most upbeat and positive person she was way back in the 1970s.

In conclusion, I'd just like to say that all the fragments and chasms of my severed life are becoming one to re-create a whole Greg Umlauf, and I have all the people in this story to thank.

Greg Umlauf

Advocacy & Peer Support Services

One of the central themes identified in many of our stories is the benefit of working as advocates and peer supporters. Countless individuals in recovery have discovered the rewards of helping themselves by helping others, and yet ways of tapping into this powerful asset have presented a difficult problem for our traditional public mental health care system. These supportive roles, at drop-in centers, as advocates, in self-help groups, as peer specialists and others, provide meaningful work and foster empowerment (Forquer and Knight, 2001). To foster community integration, states are looking for successful and cost-effective ways to treat people in the community. It is important that plans include peer supports and peer-run services as key elements to recovery and successful living in the community *(Community Integration Now! 2002).*

For years, funding agencies and providers resisted financially supporting peer-run programs, but as consumers united behind the principles of peer-support, state agencies and other sources of funding began to increase opportunities for financial assistance and to encourage independence from provider agencies (Community Integration Now! 2002). Peer-run services and supports began to expand, and innovative ideas began to flourish. Today, groups of consumers throughout the country have started an impressive variety of businesses and services, such as self-help centers, advocacy groups, vocational and computer training, and respite care. “The proliferation of offices of consumer affairs in state mental health agencies, statewide consumer conferences, consumer-directed technical assistance centers, and peer-run support services, and the growing respect for consumer/survivor research and policy professionals are indicators of a vibrant culture of collaboration today among consumer/survivors and professionals” (Clay, Schell, Corrigan, & Ralph, 2005).

Another highly important area in which states can assist in the creation of peer-run services is by providing funding for statewide consumer organizations. It is important to the entire system that consumers organize and speak with a cohesive voice, whenever possible, to inform state governments and provider agencies about their needs and desire for services. Statewide consumer organizations support the development of peer-run services throughout the state and at the local level. Consumer leadership and peer supports flourish in states with strong statewide networks. Providing funding and supports that strengthen a statewide network promotes the development of peer-run services and strategies that make community integration more successful *(Community Integration Now! 2002).*

Peer supports and services not only assist the person receiving those supports but also the individuals providing them. “Giving back,” or as one person relates in her story, “paying forward,” provides the persons in the helping role with feelings of purpose and meaning in their life and bolsters their self-esteem. “Through peer support, people with mental illness have learned that recovery does not come only from without but taps into an inner life force. They have discovered that giving feels good because it nurtures a sense of self-worth” (Clay et al., 2005).

Peer supports are based in two guiding principles: the *peer principle* and the *helper's principle*. "According to the *peer principle*, relationships are based on shared experiences, and values are characterized by reciprocity and mutuality. Within the consumer/survivor movement, a peer is not just someone with equal standing but also someone who has shared similar experiences and challenges. A peer relationship implies equality, along with mutual acceptance and unconditional respect. The *helper's principle* is a corollary of the peer principle. It means acting for the benefit of both oneself and others. Consumer/survivors believe that working for the recovery of others, especially one's peers, facilitates personal recovery for both" (Clay et al., 2005).

Consumers working within the system as advocates play a key role in assuring that people receive the services and assistance they need. Advocates assist people in grievances, rights' protection, and navigating the complex systems of care. Consumers as advocates not only understand the system as professionals but also through their experiences within that system.

For years, consumers working within the traditional mental health system have faced opposition to disclosing their identity as recipients of services. However,, as the system has slowly come to recognize the value of the peer relationship, the inherent stigma has lessened and an expanding group of peer/professionals has emerged. This combination of experience and professionalism brings added value to every level of service provision.

The development of certified peer specialist positions requiring a high level of training has created new avenues for funding peer supports. Many states have worked closely with their state Medicaid agencies to assure that services provided by these professionals will be Medicaid reimbursable. Although there are many consumers working as "peer specialists" across the country, many of these positions have required little or no specialized training. By accrediting these positions through the certification process, a higher degree of professionalism is achieved. At this writing, the Florida Substance Abuse and Mental Health Office, in partnership with The Florida Peer Network and the Florida Certification Board, is in the process of creating a certified position. This will open up new possibilities for consumers working in mental health services.

Peer specialists can provide a wide range of services to other consumers. They work in crisis centers, drop-in and advocacy centers, long-term inpatient settings, respite facilities, and Offices of Consumer Affairs. They run support and self-help groups, participate in dispute resolution, provide peer counseling, and help in preparing advance directives. Peer specialists are also beginning to fill more traditional roles as supportive living coaches and resource coordinators (case managers).

Peer-run drop-in centers and recovery centers are far more effective than centers should provide all of these things and more. It is not a destination; it is a path to recovery and reconnection with the greater world.

“Although many drop-in centers do not consider themselves a part of the mental health system, all consumer-run drop-in centers fill a unique and important role in (or around) the mental health system. For a fraction of the cost of clinical mental health services, a drop-in center can provide a supportive environment for consumers who might otherwise resort to hospitalization or other costly services. Many drop-in centers offer services on evenings, weekends, and holidays, when clinical mental health services might be unavailable” (National Mental Health Consumer’s Self-Help Clearinghouse).

Many centers incorporate small businesses into their organizations. Having these allied businesses co-located with a drop-in brings the community into the center. People interact with each other in the normal course of business, whcih helps to demystify what a drop-in center is and to reduce the stigma of mental illness. These businesses can become an important source of income to the centers and provide low-cost services and goods to its members. Some centers have food pantries and clothes closets to help consumers living at subsistence levels.

Stories of Survival & Recovery

Someone Who Believes in You

Dixie Merchant works as a Peer Specialist for a Florida Assertive Community Treatment team and is a recipient of services from another. Over the years, she has come to terms with living with her illness and the years of abuse she experienced. One of the key elements in her recovery was meeting a person who believed in her ability to survive and thrive. That meeting was the beginning of her journey to rebuild her life. Along the way, she discovered the power of peer and family support, having her own place to live in the community, a livable income, and the necessities to live. She tells us about the importance of access to services, giving back, the self-esteem of meaningful work, and the loving support of her faith. Every day, Dixie offers the benefit of that knowledge and the strength she has gained to the people she works with.

My name is Dixie Merchant. I would say that the worst of what I have experienced was all within the recent past. It was a several-year odyssey, but it has resulted in a joyful life’s pursuit. Thank God I was one of the people who escaped. Thank God I was a success story and I can say that I have a fulfilling life. That’s a lot more enjoyable to say because of what I have come through. You love so much when it is over. To have stability of mind is wonderful.

One of the things I suffered from was intense delusional paranoia. I guess I highlight that because it was one of the strangest, most odd, far-from-reality experiences I can imagine. I distinctly remember that I thought that if a person had a folder, there was something in it that was about me. It was as if someone else’s existence, what they were doing, what they were pursuing, was always related to me. That egocentric, disproportionate focus on self is not reality. I don’t care where

I was diagnosed at the CSU and in the psychiatric ward. Then along came Marcie, who told me about the FACT team. I don't know how on earth I met her. The only time I remember was when I was in the hospital. She seemed to know me at that point, so I don't know if I met her some place else or what. All I know is she walked on to that unit and told me I could get medicine because of the FACT team. She assisted me with the application, and that's when I knew help was coming. She was that fork in the road. I will never forget the significance she had in my life — never, never, never. She was kind. She was smiling and she cared. There is something genuine that you cannot fake and she had it. She truly cares about people. She doesn't have to have a long-term relationship with a person. Always, from then until now, she has raised the bar of belief in me, even more than I have. She still does that to this day. She believes that I can do it, more than I ever did, and when you're in the trenches and you don't believe in yourself, you don't even respect what you think about yourself, any caregiver is an authority. Thank God I was one of those people who respected authority. She always says to me, "Look where you've come from."

I don't know how long it took, but the medications worked for me. I was always compliant with my medications. The thing I remember most is that they lifted off all of the negativity, and underneath I was fine. I just felt fine; you could say, normal. I felt as if nothing was wrong. I went from agony — and I don't take that word lightly — I mean from agony to everything is fine. That's what medication did for me. That's why I am such a proponent of it. I was prescribed Zyprexa, which made the psychosis and the paranoia disappear. As I took the drug, I remember being impressed every day because I started believing all those things less. I saw, felt, and knew the dramatic difference daily. I knew the medicine was working. I don't get psychotic now. I'm a proponent of medications because I will never forget what they have done for me.

I've never actually had therapy. I never thought it was necessary because it was the medicine that was curing me. Now that I work on a FACT team with therapists, I see how they relate with others. The team was there for me. They provided me with crisis-related services, they were there for me, and they cheered me on. The two big things they did for me was cheering me on and supporting me. I remember

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They saw something in me that I didn't see. I didn't even think there was anything there.

advocating the downtrodden. I like working with forensic clients; they're at their worst when they go into jail. I want to be of help when they are at their worst because that's when Marcie came to me. That's where I received my help, when I was in the psychiatric ward. That's why I like to work in the courts, the jails, and the CSU. I like to be the one throwing the lifeline. That's where I want to assist, and people know that. People see that, and they respond, and it is helpful to them because they know that I am there.

This work gives meaning to my life! It doesn't add just a little meaning; it is the meaning in my life. My life is getting exponentially broader because of this. It's like clouds rolling in. They just get wider, longer, and deeper, and there's more and more every day. Each day, you expand in terms of the support you give to somebody. You're able to participate more fully, devote yourself more, and give more because you have capacity each day. For some reason, being in the particular situation with the person helps us develop ourselves as people.

My daughter and I were separated for a very long time. She was with her father, and she was very restricted. He was a tyrant. She had to wear the same clothing for 3 years. The school would call him and say, "You can't put these kinds of clothes on her because they're too small." She went through that. Then, when she came to me, I would let her do anything she wanted. I bought her everything I could. The balance came after that. Now we are very active in church, so we pursue our spirituality together. That is the most enjoyable thing, and as a mother, anything my child pursues is something dear to my heart. Our relationship is about doing things together, but it is also about open communication. We share everything and we don't have fights. We don't have a lot of stresses; we have issues. I can only provide so much for her, and she can see what other people have and that's an issue for her. She's so sweet, she says, "I know you can't do everything but sometimes this hurts me because I don't have this or that." She's not in any way manipulative, and there's no guilt or anything like that, but as a mother, I wish I could do more. She understands my limitations, though.

We share our hurts and our joys. Every day we do a Bible verse. This is a good thing, an issue and a prayer. First, we each read one verse from the Bible. That's kind of our opener. We then discuss an issue, and we do a good thing. You could look at it as a "thankful for." Finally, we end with a prayer. We just made this up. These are some of the things we do together and I can say, and I know she would say the same thing, that our relationship is richly rewarding.

My life's pursuit now is learning my job. That's what I want to do. I'm moving closer to my work, and I will be able to devote more of my energy to it. My daughter is going into high school. She has many of friends, and she is a really good singer. I watch her going through life because there is only a certain amount of time I will have with her. I've learned that through all of my traumas, I only have so much time to be with her and to watch her grow up, so I am trying to do that now. Then maybe she will get married and maybe I will, too. I have no interest in marriage now because that would take time away from her and my job. Once she's gone, I will want to add something at that point. So then I will, but for now I am just so comfortable with getting over the trauma. She and I went through the unbalanced state, and now everything is leveling out. My job, my daughter, and moving are my goals for now.

The future is so bright, so good. It is filled with promise. That is the best way to say it. My daughter and I have our whole lives ahead of us. I always feel as if I'm forever branching out. It is the way it is supposed to be.

Dixie Merchant

Donna Griffin is another one of us who struggled with addictions while living with mental illness. She credits her recovery to a number of supports and services. Donna talks about quality care, medications, wellness tools, self-care, and the support of family and friends.

My name is Donna, and I have been diagnosed with bipolar disorder, type 2. I am 47 years old and have known that I have had this illness for 17 years.

and was extremely paranoid. I was argumentative, untrusting, and delusional. My friend quickly came home and brought me to the women's crisis center. From there, I was taken by ambulance to the psychiatric hospital, where I stayed for 2 weeks. I was prescribed medication but had an allergic reaction to it.

Shortly after that, my mother flew out to California and brought me back home. I spent 12 weeks in the psychiatric hospital back east. From then on, it has been a journey of mental anguish with many severe episodes. One time I became catatonic for 4 months. I had deep depressions lasting from 3 weeks to 5 months. Sometimes my overall depression lasted as long as 1 year. I have very little mania, sometimes for 4 days and others for as little as 2 hours.

Now for the good news. I have an excellent doctor and the newest and best medications that suit me well. I've learned to take care of myself so that my episodes are farther apart and less severe. I haven't had a major one in 2-1/2 years. Taking good care of myself consists of taking my medications, seeing my doctor, exercising, eating right, going to my bipolar support group, knowing my warning signs that an episode is coming (becoming more attuned to my own body), and using the support of friends and family.

I am happy and grateful to say my episodes are shorter and fewer. This has come with a lot of very hard work because I want to stay healthy and productive. It hasn't been easy, but I don't want to go back to where I was. I'm not saying that I'm cured but that I have gotten better. Having the services and supports I need in the community is important. I personally feel that bipolar disorder and many other mental illnesses come just because we have them, not because we are doing something wrong. It is a chemical imbalance that we cannot control without help. I have been extremely fortunate to have a support system with family and friends that I can rely on. I know that they do not fully understand what I go through, but they are supportive and loving just the same.

It has been a huge learning experience, and I've found that accepting the diagnosis is the first step in recovery. The rest will come if you take care of yourself and work with a positive outlook. If I can do it, so can you. Just give yourself a chance.

Donna Griffin

Karen Gaines is like many of us. She lives with the symptoms of her illness every day, but she is proud of the progress she has made toward recovery. Karen has found some peace and joy despite her experiences with abuse and a debilitating illness. Having people in her life who believe in her has supported her through the hard times.

I was about 24 or 25 years old when I first found out that I had a mental illness. I had been in a marriage for about 6 or 7 years. He was an alcoholic. It was very hard because he used to beat me. I had a lawn business, and everything was going really well for me. They thought that I had an anxiety, then a bipolar, disorder. Finally, they found out that I have schizophrenia. It changed how I felt about myself.

I felt rage. I was very angry, hurt, and scared. I was in much pain. I tried really hard to do the best I could do. My son, Kyle, was 6 at the time. I started doing Tae

Kwon Do with him and focused on that for approximately 4 years. I didn't take any medications or anything. I worked outdoors and that helped. I realized that I was loosing sleep no matter how much I worked or how hard I worked out. My husband was getting worse, too. The more I tried to get through things and get on the right medications, the more he fought me. He didn't want me to get well, because if I got well then I would know what kind of person he was.

I couldn't go home all the time because of the condition that he was in. If I did, he would become verbally abusive and tell me that I was psycho. Now, years later, I believe he was sick himself. He was very controlling. I wanted to get out of the marriage sooner than I did, but he kept telling me that no one would love me, or that he would take Kyle away from me. That would make me go into a rage, and I didn't know how to handle it other than to beat on myself. I would just lie on the ground, punch things, and hurt myself. I still have the scars from that. I don't know why I did that, but through the years I have found out more about mental illness and that other people also do that to themselves.

I have been in the hospital at least 10 times. The first time, I had a complete breakdown. I didn't know what was going on. I kept telling my parents that I needed help; I didn't know what was wrong. They found the local community mental health center and got me into the crisis unit. That's when I was put on my first medications.

It was scary the first time I went in the hospital, because the people in there with bipolar disorder or schizophrenia were acting really weird. It was scary. They were older, and I was wondering if that was going to be me when I was older. I couldn't sleep in the hospital because I was afraid, because I had just found out that I had a mental illness. I knew I could recover if I just worked really hard. I needed to stop being a doormat, stick up for myself a little bit, and quit thinking I was less than everyone else. I needed to have more self-confidence, to look in the mirror and say, "You're ok."

The therapist I was seeing was trying to take me back in to my childhood stuff. That was really harmful because that wasn't why I have schizophrenia. It brought out a lot of acting. I saw this therapist for a year, and it made me worse.

I decided for myself that I didn't need that kind of help; I needed something else. So I went back and saw Mary, the woman who filled my prescriptions and other things like that. Mary hooked me up with a lady named Marlene. Marlene was totally different from the other therapist, so I began seeing her. I saw her for about 2 years. I also did really well on my medications for approximately 3 years. I couldn't sleep, but I wasn't having any incidences in which I was beating myself or scaring anyone around me. Then it stopped working and I got worse. I was afraid to tell anyone because I was afraid that people would really think I was crazy. Again, I tried to commit suicide: I ran my truck into a telephone pole doing about 80 miles an hour.

The first time I was back in the hospital, I left in a couple of days because I was really scared. When I went in for the second time, I stayed for 3 or 4 days because I was going to the groups that they have, which seemed to do well for me. I was feeling a little more comfortable about being there.

I didn't have medical insurance then, so I probably stayed 4 days the next time, too. I remember staying 10 days at one point because I was so afraid that if I got out I would try to kill myself again, and I didn't want to do that. My sister committed suicide when she was 22 years old.

After my sister killed herself, I remember sitting on the front porch at my brother's house. He had a gun. I remember going and getting the gun out, cocking it back, and sitting there for about 4 or 5 hours. I was going to shoot myself. I don't know if I was scared or maybe God helped me through it, but I remember walking out and just shooting the gun straight up. When I started remembering what I felt like when my sister killed herself, I knew that I didn't want to do that to someone else. That was when my depression first started; I was 15.

During those hospitalizations, the medications didn't seem to work, but the ones I'm taking now seem to be. Things are going much better. My parents went to the NAMI Family to Family training in Gainesville so they could understand more about me and help me. When I get in my obsessive moods, they leave me alone and let me do what I need to do. My mom has been very good,

I also ended up with posttraumatic stress disorder because I afraid tha:nd let me do what well because we know about our illnesses, so it is a lot easier for us to get to know each other. Just having him in my life has made a di

Access to Services in the Community

As states struggle to comply with the principles of community integration, they face the fundamental problem of providing quality mental health services to people where they live. The idea of moving away from fitting people into existing programs and requiring that they receive their services at large community mental health centers is a key part of the concept of integration. “In order to develop a comprehensive and relevant support system in a particular community, it will be necessary to 1) develop service principles that reflect a community integration mission; 2) examine current service programs in relation to these principles; 3) determine which needed services can be undertaken by consumer/ex-patients and their families; and 4) focus on new roles for professionals” (Carling, 1995).

For services to successfully promote integration, they must engage people on their own terms and let them know how these services will meet their needs (Carling, 1995). As the process of deinstitutionalization expanded across the country, one of the first new models to emerge was the Assertive Community Treatment Team (ACT Team). This program, while providing services where people live and work, relies heavily on a medical model of care. In our rush to evidenced-based practices, we are adopting them in their entirety even when the evidence suggests that some ingredients may be more important than others. Research on the ACT model has shown that not all the ingredients are as effective as others. Elements such as team approach, small sizes of caseloads, high-intensity services, and collaboration with support systems are parts of the model that produce higher levels of outcomes (McHugo, Drake, Teague, & Xie, 1999). “Yet despite this finding, the ACT model is being adopted in its entirety” (Anthony, Rogers, & Farkas, 2003).

In Florida, following shortly behind, came more recovery-oriented team approaches such as Supportive Living Teams and Comprehensive Community Service Teams. These “wrap-around”-type models provide services to the person where they live and work and support the principles of recovery.

As state systems shift their focus to integration and recovery, they are continuing to develop services that respond to crisis needs by preventing the crisis before it occurs. Twenty-four hour “Warm Lines” and respite facilities are two methods growing in popularity. These services are often run by peer organizations and provide a high level of peer support. Mobile Crisis Teams are another useful tool to prevent unnecessary hospitalizations and involuntary treatment. In several locations, consumers are running alternatives to traditional locked-door crisis units.

Other rehabilitative services, such as clubhouses that have been in existence for decades, have begun to proliferate nationally due, in part, to states funding them partially through Medicaid plans. Because many states have moved to managed care organizations for Medicaid services, those states have begun to require recovery-oriented services and consumer involvement in the design and delivery of those services. Development of a comprehensive set of guidelines to implementing recovery-based services in a managed care environment will provide continuity of quality services throughout the nation.

In a time of shrinking or static mental health budgets, the long-standing reliance on residential-type programs and services inhibits the system’s ability to fund more supportive, recovery-oriented services in the community. Most people do not like to live in group settings, and tying services to these residential programs often creates a coercive relationship between the person and the caregiver. The majority of consumers prefer to live in their own environment and engage in services as they choose. The cost of residential programs is so high that the elimination of a few beds in a community can free up substantial funds that can be used to support people living on their own.

The traditional mental health care system is primarily crisis focused. The system concentrates resources on long-term hospitalization, crisis intervention, and residential treatment. In many states, as much as two thirds of mental health budgets are allocated to these services. To truly accomplish transitioning our systems of care to an integrative, recovery-based model, it is important to focus more attention on the “front end,” supporting people in their lives in the community. With severely limited funding, it is difficult for states to break this cycle of responding to people in crisis while underfunding preventative and recovery-oriented services.

The key principle is that services of all types need to be accessible and affordable for people where they live. Issues such as safety where the services are provided and proximity to local community transportation are important considerations. “Some advocates believe that a lack of accessible, affordable, and appropriate transportation is the single greatest obstacle to successful integration of people with disabilities into the community. However, it is one area in which advocates perhaps have the most work left to do. Many communities have no public transportation system whatsoever. Even in many places served by public transportation, transit systems cannot provide consumers with reliable access to what they need to live in the community: medical and psychiatric care, employment, shopping, social and recreational activities, and worship services” (Community Integration Now! 2002).

Stories of Survival & Recovery
Giving Back & Paying Forward

Sandra McQueen-Baker is a powerful voice in the growing consumer/survivor community. She is the Director of the Fresh Start Drop-In Center and the Miami Dade Consumer Network. Sandra is also the proud winner of the 2006 Voice Award, the 2007 Heroes In “The Fight Award, and the 2007 Eleventh Judicial Consumer Network

“Leave it to Beaver” type of family. With my mother working, it meant that family members and friends had to help to take care of my two brothers and me. In the process of others caring for us, I was being molested in our home. It took a severe toll on me because I was afraid to tell anyone. My voice was silenced because I was told if I shared this information that a particular person would harm my mother. I was afraid, and I felt alone. The relationship that my mother and I could have had was scarred, because I felt that I had to lie there and endure the molestation to save her. The thing that could have brought us so close together tore us apart because I was afraid to tell. I had no voice; I didn’t want one.

I did not know how to handle what was happening to me, so I began to sneak little miniatures of liquor and was drinking by the age of 11. I had seen that it made others feel good, so I thought that maybe it would help me to endure the torture when somebody was touching me. During that time — you can call it low self-esteem, no self-worth, you can call it voices, I don’t know what you want to call it — my head began to tell me how “awful” I was, that I was “no good,” “would never be any good,” “ never be anything,” and that I was “dirty” and I felt that way. The only way I knew to feel good about sleeping at night was to get high, drink, take drugs, whatever it took. Of course, we know it is called self-medicating today. I just didn’t want to close my eyes because I was afraid of what was there, and I didn’t want to keep my eyes open because I was afraid of who I was. Although I was a child, I was drinking and drugging and going through all these different things, and I just didn’t understand why this had to happen to me. I hated myself, and I didn’t like the world around me. So I clammed up, drank, and got high. That was my existence. That’s all I wanted; that’s all I lived for.

I dropped out of high school and I continued to get high. I even found myself dating a drug dealer. It was not out of love; it was not out of some compassion he had for me. He wanted to hide his drugs on a teenager, and I just wanted to get high every day. There was no love between either of us. I just needed to get high, and that was my life for a long time, a life of drugs. I learned to hide from police officers; I learned how to withhold and go in to pick up the right drugs. I just needed not to remember what was happening to me.

After having 2 children, I met an awesome guy who was willing to talk with me and try to understand what was going on with me. But I found out I was almost afraid of him because he came to me with a sense of normalcy and calm. In my life, I didn’t know anything about normalcy and calm. I was depressed, beat down, and worn down. I tried to commit suicide five times. Some people may say that was just a cry for help, “You really didn’t want to commit suicide.” But the truth is, yes I did. I really, really not only wanted to but felt like I needed to die because my life had no meaning. Life continued on, but this man was very persistent because he saw in me something that I couldn’t see in myself. I had a child with this man (my third child).

Immediately after my third child was born, my mother passed away. She was in the hospital at the same time I was in the hospital to have my baby. She got out a couple of weeks later and then went right back in. She never had a chance to see my baby, and I never got a chance to know the mother that I should have

downside of people but they would always get to see the afterside. We were going around talking to police officers in different cities and different areas and I just felt like my life was really coming together for me with real, true meaning.

A few years later, I was very ill with pneumonia and was home in bed on my anniversary. I remember so many turning points happening at the same time. My husband wanted a divorce. I hadn't heard from my son, who was serving in Iraq for a long time, and I was very afraid. My aunt's son, whom I raised as my own, got involved in a very serious crime and I saw his picture on television. It just seemed as if everything was coming at me at the same time and coupled with this illness. I was tired ill. I said to the Lord that I could probably work through my marriage and some of the issues that my husband talked about but I asked Him, "Please don't take my son." I said, "I haven't heard from my son in Iraq" and I didn't know how he was doing. I remember praying and reminding the Lord that I had tried to be a good person. I've gone through the illnesses, I've gone through everything — the drugs, the alcohol, everything and I've tried my best. And I said, "Lord, please, please, please don't take my son away from me." My husband and I talked about our issues. We were able to work through our differences. I take time now to remember that I have a husband and I don't care what my priorities are, my God first and then my family. I want to heal the world and do all those things that people with an "S" on their chest can do. I want to make a difference. I want to shout to the world that you can recover, but my priorities are my God, my family, myself, and then all those others. If anyone resents that, I cannot apologize because I still feel that way today. I will not change from that. Do what you will; that is what I believe.

I can remember being at the Drop-in Center one day, and my oldest son called me and asked me to do him a favor. I quickly responded, "Anything." He said, "Could you please come home and open the door because I'm standing here and I don't have a key." I flew home to see him and to let him into the house. I was so happy to see him! I wanted to check his fingers, toes, and eyes. I wanted to make certain, just as when he was first born, that everything was appropriately still there. I just kept on thanking God for His kindness, yet once again to me.

The vision of my agency has expanded immensely. Fresh Start Drop-In Center is still in operation. Kudos to my staff, Zeronie, Octavia, and Val, and thanks to Sister Betty. Several people have been instrumental in implementing the Consumer Network Project to empower consumers and provide a venue for them to develop leadership skills. I also must give thanks to Cindy Schwartz, my supporter, and to the District Eleven office of the Department of Children and Families for introducing Mary Ellen Copeland's WRAP training and supporting the individuals in our area. I became a WRAP facilitator and enjoy training consumers, staff, and providers on this initiative. I was born to WRAP.

Each morning, I am so grateful that God spared my life, looked beyond my faults, and saw my needs. I'm grateful for the medications and I'm grateful for the therapy. I'm grateful for everything that it took: each case manager, psychiatrist, therapist, medication, and supporter. It takes a little of everything to enable you to make it when you are a consumer. It takes food, clothes, people to help you get from point

A to point B. It takes a cheering section. It takes any and everything in order for one person to make it.

It is my belief that when one person makes it, that person should reach back and pull someone else up because they should be mindful of what it took for them. So I'm always reaching back or paying forward because I believe that every time I help someone, that person will help someone else and they, in turn, will help someone else and we are all going to pay it forward.

I believe in recovery. I know it's a possibility because I have to look at myself every single day. I believe in the spiritual aspect of my life. I will not change from who I am, and I know that it was my God, the love of my God, the Lord Jesus, who pulled me through at times when I could not help myself and should have been dead. I enjoy what I do and the life I now live. I enjoy laughter and seeing the laughter in others. I know recovery is possible. I've said it so many times, and I'll say it 20 more times because I know it is true,

It takes hardships. There will be times when you will ask, "Do I want to live today?" But I have the answer. Yes, you do. If not for yourself, for someone else who is patiently waiting on you for that kind word, a gentle pat on the back, that loud roar in the cheering section to point the way to help, happiness, wholeness, and joy.

I'm happy today!! I'm happy and it took every treatment, support, therapy, and every medication that I needed. It takes everything to make it, but in that recovery phase while you're feeling real good, you may have a setback. It doesn't mean you can't come back. The same or a different support system will be waiting for you, and you have to reach out and ask for help. You can't get help if you hide from it; you have to ask for what you need.

I'm grateful to be here today. I'm grateful for the hard times, not necessarily that I loved them but because they taught me how to endure. I'm grateful for the good times. I'm grateful that I have a voice and that every person who is experiencing recovery does have a recovery story.

I'm so grateful to have been invited to the Consumer Voice Awards conference and, more so, that I won the 2006 Consumer Voice Award and the 2007 Hero Award. I find such irony in winning because I was the woman who had no voice, so whenever you see me, you're going to more than likely see a smile on my face because I'm grateful, happy, and joy filled, knowing the joy of the Lord is my strength. I hope that my life and my story will not only be of some help and support but also mean something to someone else.

I asked the LORD for things that I may enjoy Life

Instead He gave me life that I might enjoy all things.

Anonymous

Sandra McQueen-Baker

anything. The doctor suggested I see a psychiatrist. This was my first experience with a psychiatrist, who said what I was going through was normal. I just had a baby; back then, they called it "the baby blues." "You'll get over it and everything will be fine," the psychiatrist said. I wanted to scream at this doctor, "Everything is not going to be fine! It's not fine!" My depression really progressed from there, and I really only just existed. I did what I had to do to take care of my daughter and be a wife.

My first manic episode was in my mid to late 20s. I went on a major spending spree. I bought for myself and everyone else. I don't mean five dollar things either. I maxed out all of our credit cards, took all the money out of our checking and savings, and left us with nothing. My husband didn't know at first because I always handled the finances. When I started coming out of the mania and into the depression, I realized what I had done. Bills were coming in, there was nothing in the bank, and I didn't know what to do so I had to tell him. He was livid! He didn't think this was because of a mental illness or anything. He just thought I was this horrible person to have spent all the money with no regard for how hard he worked or anything. This was the beginning of the decline of the marriage. He started seeing my best friend. Then one day, out of the blue, he told me he wanted a divorce.

Once he left and I had to tell the family what was going on, they were very supportive. They found me a place to live with my daughter. My daughter was 5 and it was hard on her. One day I received a call from school that she was upsetting other children because she was telling them that her father died. The school recommended she see a psychiatrist. When I would take her there, I would think to myself that I was the one that needed to be seeing a doctor.

It was about a month after my husband left when I decided I just couldn't take it anymore and swallowed a bottle of pills. My parents had gone away and had taken my daughter with them because they thought this would be good for me. My brother, who was about 18 at the time, was the one who found me. I remember it like it was yesterday. He was shaking me and screaming at me, "If you don't tell me what you took, I'll kill you!" Now, years later I feel so bad for putting him in that position. That was my first suicide attempt.

Within a year, I really went manic! I went through all that I had left. I had a job as an office manager and was PTA president. The PTA needed to raise money, so I thought the best way to do this was to raffle off a car. My position as an office manager gave me check-writing privileges, and I chose to use those privileges to purchase the car for the raffle. I never thought what I was doing was wrong. I justified my actions. I figured since my boss was always donating money, this would be like donating money to the school. I thought I wouldn't have check-writing privileges if I weren't allowed to decide where to write the checks. During this time, I never thought I was manic or realized anything could be wrong. Then, of course, I swung into the depression and realized what I had done. I went to my boss and told him about the car. He didn't take it too well. He pressed charges and I was arrested.

However, some people at the hospital did seem to care. It seemed as if I would always find them somehow, or they would find me. I really don't know which. Toward the end, I was refusing to leave the hospital. They tried several times to discharge me, and I would go into such a depression. I was afraid to leave because although all this hellish stuff was going on, I still felt like I was safer there than in the outside world.

Finally, they moved me. I was like a pilot project. There was housing where some of the doctors used to live on the grounds of the hospital. So they started this program in which some of us started living in those cottages. We would cook for ourselves and do our own laundry, etc. These cottages were our own little apartments.

They thought it would be good for me. They thought that once I saw what it was like to be on my own again, I would want to go home. In my eyes, it wasn't bad because it was like I was at home but still in their environment and still protected. Eventually, they realized this and assigned me a guardian advocate who was an attorney. He would come and talk with me for hours, trying to convince me to try to leave on my own. I just kept telling him no, that I was fine. I had a plan and when I reached old age, I would go to the geriatric ward and die there. I was serious. I told him I was fine with this and I was. I was content and there was no problem. I had a little job while I was there as well. The staff took me under their wing and would talk with me. They would tell me how well I was doing, that I really did need to get out there and try and think about my daughter.

While I was in the hospital, my husband filed for custody. That was really the final blow when I lost custody of my daughter. She didn't want to see me either because she felt I had abandoned her. So our relationship wasn't good. She only saw me because they made her. There was no emotion, no affection, nothing, whenever I was around her. If I would try to hug her, she would stiffen up like a board.

So I thought I didn't have anything out there and I would stay at the hospital. Finally, I felt sorry for the guardian advocate because he kept coming up there and pleading with me, so I thought, "Okay, I'll try it." They tricked me. They said I would just go for a week to this supervised housing through the community mental health center in the town where I lived. So I just packed a few things, unaware that they had packed all my stuff. I wasn't too happy when I found out this was what was going on. I lived in the supervised apartments for a year before graduating to an apartment I shared with only two other residents. I think there were six apartments in total, so I still kind of knew everyone and a staff member would come once a week.

At first, I was very dependant on the staff. In the supervised apartments, the staff was just downstairs from us. I was constantly in the office. I felt like I couldn't do anything. I felt like I didn't know how to shop or cook. Prior to all of this, I managed an office of 25 people. I was an excellent cook. I even cooked in a restaurant.

Now it was like a learning process. I had to be taught all over again how to live. When I think about it now, I can't believe I had become that way. I would say the first year was the hardest. Then one day on my way home from cashing my first paycheck, I was mugged. Well, I had such a fear of the police that I wouldn't let the staff call the authorities. They said they had to, though, but I didn't want any part of it. Whenever I would see a police car anywhere, I would just start trembling because in my mind, I thought they were there to get me.

Once I had been in the unsupervised apartment for a year, everyone thought I was doing well and should get my own place. So again, my parents came. I was still not making any decisions. Either my treatment team or my family was making all my decisions for me, and I was fine with that. While I was in the hospital, my driver's license expired. For some reason, I developed a fear of driving so I waited about 4 years before I even got my driver's license again.

I got my own place, which was very hard at first. I couldn't sleep at night because I was very frightened to be alone. I was working at this cute little café. I loved it because I loved cooking and baking. To me, it wasn't even like a job because I loved going there every morning. I loved the peopl. I lo

and it was when my father was first diagnosed with Alzheimer's, and my mom was having a hard time. My siblings then decided I would move back home.

I had gotten back together with my family by then, but it wasn't the same. They never included me in things unless I was sitting there. When they would call me, it was always superficial. It was never as it used to be where I would always know what was going on. It was 4 or 5 years that we talked like strangers, but now they needed me again. My doctor, therapist, and case worker diligently tried to convince me not to make this move because they felt it wasn't a good situation to be so close to my family. All I kept thinking about was how my father would always come and visit me and now he needs me.

I moved back to Lehigh. My case manager had told me about a new program called Compeer. She wanted someone to come and talk to me about the program. I said no because I felt like it was just one more person to come into my home and get into my personal business. I felt as if I were an open book after being in metal heath treatment for so long, so I just said no. It was about a month later that my case manager asked me again. She said she wouldn't ask me if she didn't think it was something I would enjoy. I still wasn't getting much socialization; I was in a little cocoon. I would visit family and church and that was it. So I finally agreed to let this other woman come and tell me about the program. I just figured she up at a time. Eventually, I became okay. I really believe that the calls were what got me through it because I was very low and was having suicidal thoughts, which were very scary.

Then I became a member of NAMI. I used to say that I was dragged into these big difference. I have always felt very comfortable in a support group with people more like me. I am able to speak what is on my mind and not be judged. That was actually huge for me. I didn't think anyone cared before that.

Now I think they do, even my parents. In the past, they didn't ask me anything about my life, like what I was doing with NAMI and things of that nature, but now they do and they are genuinely interested. This makes me realize that maybe they are starting to understand that they need to become educated about my mental illness, too.

They are proud of me now. Only one person has actually verbalized it, but I can tell they are. I think it bothers them that I have become so independent because I was without supports. In fact, it is less when you compare it with statistics involving homeless individuals using alcohol and drugs. People with mental illness are, in fact, 2.5 times more likely to be the victims of violence than the general population. Collaboration between consumers, mental health professionals, law enforcement, local governments, and other stakeholder groups are valuable tools for reducing violence and maintaining safety in our communities. Crisis Intervention Team (CIT) training for law enforcement agencies is an excellent example of these collaborations.

A Vision for Tomorrow

Recovery is real! It takes place every day for tens of thousands of people around the world. When people tell their stories, they give us a glimpse into the complicated process of achieving that recovery. As we have said, recovery is as individual as we are. If we look at the things that have been identified as important by the people who have told us their stories, we can see many of the common threads necessary for a recovery-oriented system. We have chosen five of those elements to discuss throughout the book and propose how they can be incorporated into a public mental health care system. But, as you can see, our storytellers list many more that we have not discussed in detail. Here are some of these elements:

- Education
- Friends & Family
- Basic living needs
- Self-help programs & materials
- Co-occurring treatment
- Creative outlets
- Hope
- Respect
- Someone who believes in you
- Trust
- Access to medications
- Spirituality

So, if we were to close our eyes and imagine the perfect mental health system, what would it look like? What a wonderful thought!

Our perfect system would be built on a sound underlying social structure; in this structure, people would have the basic supports that they need to live in the community. These would include a livable income that keeps people out of the dire circumstances of extreme poverty. They would also include a safe, decent, affordable, and private place to live as an integrated part of the community, including rental assistance as needed. Also, for those wishing to partake of the American dream and own their own homes, home ownership assistance programs would be available. Another basic societal support would be safe, convenient, affordable transportation that would not only allow people to access that service but also, even more importantly, allow them to access the community around them. Just living in the community is not enough; it must be accessible and available to everyone.

We envision a system that is genuinely person centered. In this system, programs such as Self-Directed Care would be a primary way that people access their mental health care and recovery needs. System Navigators would assist people in finding their way through the confusing array of public health care services and supports. People needing additional support would find a system oriented towards recovery and the needs of the individual. The increased use of mechanisms for providing incidental funds to individuals would offer additional financial assistance to meet their recovery needs.

Deep-end services like crisis support and long-term hospitalization and residential programs tied to services would be needed less because we would support people in their wellness and prevention needs. Self-help programs such as WRAP would be available through consumer-run services. All people would have access to the medications they need despite their financial status. Services would be provided in safe and accessible areas of the community and would be available without long wait times or delays. Professional staff would be well trained in the concepts of recovery and would understand the importance of supporting people in their choices and believing in their ability to succeed. Increased emphasis on providing integrated treatment for persons with co-occurring disorders would be a mainstay of the system.

Peer-run services and peer supports would be the norm, not the exception. Drop-in centers, clubhouses, respite services, and other services would be run by people who understand their purpose and importance because they have shared the peer experience with the people they serve. Peer specialists would serve in a wide range of positions including traditional roles such as resource coordinators and system navigators (case managers). Consumer-run creative coops would help people tap into the healing power of creative expression. Leadership and advocacy training would be widely available to help people become advocates and peer supporters and gain the benefits of helping oneself while helping others. Well-trained advocates would assist people in overcoming the barriers to receiving the services they need. These advocates would hold positions of respect and authority within the overall system.

True Supported Employment, including supported volunteerism, would be available to all consumers, not just the few who can now access those services. Peer-run employment programs and agencies would offer support to people across a wide range of employment options. Funding opportunities and small business assistance would be available for people wishing to start their own business. Technical assistance and mentorship would provide real world experience in setting up and running small businesses. People would have the opportunity to resume their education and continue it to meet their goals. Supported Education and Learning Centers would help people address the full array of learning needs. Scholarships and loans would be available that are specifically tailored to people living with psychiatric disabilities.

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