



COMMON THREADS

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*

The Florida Peer Network, Inc.



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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 whose lives were disrupted for many years emerge to lead productive lives through treatment or rehabilitation programs. Programs such as Self-Directed Care allow people to choose the kind of supports that they need to get on their feet again. Over and over again in these recovery stories, we find that education, employment, and housing are at the top of the list for getting on the road to recovery. Also featured are case management programs such as the Florida Assertive Community Treatment (FACT) program and community-based services offered by the National Alliance on Mental Illness (NAMI) and the Mental Health Association (MHA). However, our storytellers emphasize that personal attention and support in these programs made all the difference.

The most striking element of recovery in these accounts is the human element of compassion and kindness. Almost every storyteller in this book attributes an important aspect of his or her recovery to some kind of face-to-face contact with another person—a mentor, friend, or family member. In these cases, there is the feeling that there is at least one other person who is “on my side, no matter what.” That person may be a doctor or a therapist, but even an old school friend, spouse, or daughter may provide the impetus to recovery.

More and more often, recovered people themselves provide the needed support. In recent years, the mental health community in Florida has embraced the idea of

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 treatment programs, mental health consumers have worked for years as advocates and supporters for their peers. Whereas the formal mental health system plays catch-up in promoting consumer-driven services in mental health, there are those of us who have been around for years, quietly instituting what we call the “helper principle”—acting as advocates and mentors for our peers while bringing about our own recovery. Mental health consumers in Florida and elsewhere have established hundreds of peer-run services such as peer support groups, consumer-operated businesses, and especially peer-run drop-in centers. The Fresh Start Drop-in Center, described in the story by Sandra McQueen-Baker, illustrates the model that mental health programs around the country now follow in trying to transform mental health services into programs that will foster recovery instead of obstructing it.

The editor of this book, Patrick Hendry, has been working as an advocate and peer counselor for more than 15 years. After many years as a documentary filmmaker and later as a dealer in precious stones, he was diagnosed with bipolar disorder in 1991. Within a short time, his mother, brother, and oldest son were also diagnosed, and this was the impetus for a major career and life change. In 1992, he cofounded the Mindmenders Foundation, an organization run by persons with mental illnesses that contracted with the state of Florida to run two drop-in centers and teach peer counseling. He has also been a member of the board of directors of the local MHA and NAMI.

Patrick is currently the Coordinator of Advocacy Services and Consumer Affairs for the Florida Department of Children and Families in District 8. He is a founding member and currently Executive Director of the Florida Peer Network, an independent organization of and for people who are recovering from psychiatric disabilities and co-occurring disorders. The stories in this book are the fruit of interviews that Patrick conducted with other members of the Florida Peer Network.

Sally Clay
Lake Placid, Florida
August 13, 2007

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 never recover, that the best we could hope for was to control our symptoms, and that we would probably never work again, or if we did, the job would have to be simple and stress free. We were given the message that we could never experience the hopes and joys that enrich our worlds. And many of us believed that message. We lived day to day in fear that our illnesses would overcome us. We lived lives of deprivation, afraid to expand our vision beyond the dreariness of day-to-day living.

And then, slowly, our vision changed. We found strength where we expected weakness. We learned ways to adjust our lives, to try new things, to regain the losses we had experienced. And we learned that new word, Recovery.

It is often said that recovery takes on as many forms as there are people experiencing it. Recovery is as individual as we are. It is different for each of us because our experiences with our illnesses and the losses that come with that are different for each of us. And yet, there are common elements to those losses. People lose jobs, relationships, homes, and possessions. Self-esteem, security, and potential slip away, along with the loss of valued roles and responsibilities. These losses can be so great that people begin to feel that they have lost their identity and their future.

But, as we now know, these losses can be recovered. We can regain our sense of self, and we can look to the future again with hope. And as with our losses, the things that can contribute to recovery have many common elements. Some of the things we know that help us on the path to recovery include a livable income, a safe and decent place to live, and services of our choice that are available in the community. We need the support of our families, friends, and peers. We need someone who believes in us. Goals, respect, security and continuity, and meaningful activities in our lives such as work or volunteerism are all important.

The following stories are tales of survival and recovery. These individuals have found their own way on the road to regaining their lives. Many of the people in these stories have lived significant portions of their lives in psychiatric institutions, and only through their strengths have they found their way back to the community. Throughout these stories, we find those common threads that support us on that journey. As we identify these elements, we will look closer at methods for supporting them in our public mental health system.

In these tales, we hear about the importance of education and peer support. The consumer/survivor movement has made tremendous headway in developing peer-run services and educational programs. Organizations such as the Florida Peer Network help us to remember that we are not in this alone and that our shared knowledge is a valuable asset to be used by each of us individually.

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 Systems for People with Psychiatric Disabilities*, listed this additional series of core values:

- “Success in housing, work or social relationships is primarily a function of whether an individual has the skills and supports that are relevant to that environment or relationship.

- 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 of those medications were so horrible that I never stayed on them very long. I found the best alternative was "self-medicating" by abusing alcohol and drugs, which I started at age 14.

I graduated high school and received a scholarship to attend art school. Because I wasn't in a liberal arts curriculum, I couldn't avoid the draft. During this time of unrest in the United States, everyone was trying to find some way to beat the draft. So my telling the Selective Service that I had been diagnosed with paranoid schizophrenia didn't work; no one believed there was anything wrong with me. I wound up in the Air Force, and, after completing Basic Training, I was sent to flight school to be trained as a load master on cargo planes. During my years in the Air Force, I was hospitalized several times, but once again I was written off as someone who was just trying to get out of the service so I wouldn't have to go to Vietnam. Because of the job that I was trained to do, my skills were critical to the efforts in Vietnam, so I found myself there for 18 months. Once again, I found myself using "self medication" to see my way through my tours of duty. After finishing a 3½-year term of service in the Air Force, I was honorably discharged. While in the service, I took correspondence courses in landscaping and floristry. On discharge, I returned to college and managed to complete my education, although it wasn't in fine arts, my first intended study and life's passion. I moved to Naples, Florida, in 1970 and started a small landscape company that grew over the years to a large company with many employees and accounts. In 1984, I sold my company and took a job as a property manager for a wealthy family who wanted to develop 35 acres of gulf front property into a private compound for winter retreats. During these years in business, I was hospitalized many, many times, and because of the medical model, I had little alternative but to go along with "doctor's orders," not realizing that I should have had a say in my treatment.

When I was 35, a doctor from Northwestern University began visiting Naples in the summers to do research on mental illnesses. He was working part time at our local community mental health provider, which in the 1970s was just a storefront organization. After seeing him for more than a month, he diagnosed me as

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 people who were suffering in similar situations. We joined together and formed a support group that was solely geared toward major mental illnesses. At first, the group was met with a great deal of skepticism by the medical community, but with time we gained the respect of the doctors because of our successes. I learned a great deal from my fellow consumers about medications and therapy that could serve as alternatives or enhancements to my treatment. I have been on several of the newer medications, and, since then, my life has taken a turn for the better. I have devoted myself to psychiatric advocacy and improvement of the mental health delivery system. In 1990, I opened a drop-in center in Naples, which I ran for about 5 years.

In 1990, I decided to devote my life full time to advocating for improvement in the mental health system. Through the years, I've served on countless boards and committees devoted to mental health. I'm thankful that during that time it became important for individuals with mental illnesses to have a seat at the table so our ideas and thoughts would be included in the decision-making process. I'm equally thankful that many of us have accepted this invitation to join in to make the mental health delivery system more recovery orientated. We've come a long way over the years, but we still have a long way to go to make the system work for us.

In the mid 1990s, I began seeing a new doctor, who diagnosed me with schizoaffective disorder, bipolar type. Although this term is a mouthful, I bring it up to hopefully share with you the same situations you've experienced as I have had regarding changes in medications, diagnoses, and everything else. Until this point, I went along with anything the medical community told me or said I should do. The new doctor I was seeing believed in recovery, and she directed me to the path of recovery that I follow today.

Now that I've told you a little about my life and the journey I've taken, I'd like to give you a couple of my thoughts on recovery and how I've attempted to attain and maintain it in my life. I don't think there's any one way for someone to share recovery that works for all. I believe it's a combination of different successes combined that work for an individual. Our illnesses are unique to each of us; just as with medications and treatment options, our recovery is equally unique for each of us.

First, let me start off by saying that to succeed, you have to become the center in whatever treatment you are offered. By this, I mean you must not let others dictate what is best for you; you need to become involved in all of the options available to you and make an informed decision that fits your needs. Educating yourself is the key to success. Don't be afraid to ask questions, express your opinions, or take charge of your life. Working with your doctor or treatment team as an equal

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 severely 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

Bill Schneider, MSW, like Jeffrey, has been a leader in the consumer/survivor movement in Florida for decades. He has helped create many of the most innovative, creative peer-run services in the state. Among Bill's myriad of accomplishments, he is a founding member of the Florida Peer Network and the coordinator for the Office of Consumer Affairs for Broward County.

Bill's story of recovery from years of desperate illness and homelessness is an inspiration for all of us. He speaks about the importance of quality services in the community, disability benefits, meaningful work, and having a safe and private place to live. He also speaks about friends, family, education, self-advocacy, and advocacy for others. Bill lives day to day with the symptoms of his illness, schizophrenia, and yet he continues to grow stronger and more capable, with the ability to expand his horizons.

I grew up in a normal family, and I was a bright kid—IQ of 140, a straight-A student. But while I was in college, my concentration began to disappear. I began to hear voices telling me that I was nobody and that I was never going to make it in life. My grades dropped from A's to C's. In 1977, I was hospitalized for schizophrenia. I was given electroconvulsive therapy, huge amounts of medication, the whole 9 yards. The voices stopped temporarily then, but they weren't gone for good. After my hospitalization, I tried to find a job and make it on my own, but I couldn't take it. The voices would be just terrifying. Eventually, I moved back in with my mother and, soon after, was sent to another hospital in Jacksonville, Florida.

I was in and out of the hospital and had day treatment for a while, as the voices came and went. Sometimes I felt so good that I was in denial about my illness, until the symptoms returned. I was so tired of treatment at this point, tired of the stigma I felt from my own mother and even my psychiatrist. He'd told her I'd be disabled for the rest of my life, and she believed it. Neither of them thought that a person with a mental illness like schizophrenia could recover.

I couldn't stand the stigma, so I moved out. My plan was to find a job, but I ended up homeless on the streets of Ft. Lauderdale for 6 months. I had no food, no medicine, and a job working in a concession stand. I was very symptomatic, psychotic, hearing terrifying voices, seeing visions, and needed to be taken to a crisis center. For a while, I was living in someone's garage, and in exchange for the living space, I had to do all kinds of work. Eventually, when my symptoms became more severe, I was taken to a crisis unit.

For the next 7 years, I lived in an assisted living facility, and although that was as much a problem as it was a help, there is where my story turned around. For the first time in my life, I connected with a social worker at the facility who helped me get case management, Social Security, clothes, food, and shelter. My insecurities about living alone started to dissipate, and I felt motivated. This was the beginning of my recovery.

I was prescribed newer, more effective medicines, and a drug called Risperdal (risperidone) finally made the voices disappear for good. I was able to live on my own in a regular apartment in the community for the first time. I learned basic coping skills from my case managers and friends, as well as from consumer

advocates who had experience in the mental health system. They taught me how to advocate for myself. Their help was so important in my recovery process; it made me want to give something back. Thus, I started telling my own story to consumers. Amazingly, I found that doing this not only inspired others but also helped my own recovery. The momentum kept building like an upward spiral.

After 20 years, I finally went back to college. Some case managers doubted me and said I shouldn't apply for student loans because I might not be able to make the necessary grades. In the 1990s, however, I earned my bachelor's and subsequent master's degree in social work and consistently achieved straight A's. At this point, I was completely independent. I was off Social Security, Medicare, Medicaid, and subsidized housing. I now own a condominium through a rent-to-own program I created, and that's where I live—with my wife (did I forget to mention that I got married?).

I have continually worked on my recovery, learning what works and what doesn't. I'm now a full taxpaying citizen in our society. I have hundreds of people in the mental health system who know me. I have a very strong support system with my wife, advocates, and friends. I'm proud to say that I celebrated my 13th wedding anniversary in March 2007. Even my family accepts me back and supports me. Working on recovery pays off big time!

Now, I'm the coordinator for the Office of Consumer Affairs in Ft. Lauderdale, an office funded by the Florida Department of Children and Families, advocating for the rights of consumers in the behavioral health care system. I supervise peer specialists who are sharing their stories the way I shared mine. When my organization conducts focus groups with consumers, they usually say that what helped them the most was a little bit of everything, not just medicine, not just therapy, not just financial stability, etc. All of these elements are important to work on, and they're different for every consumer. Recovery is an individual thing. No one can tell you how to do it; the important thing is to know you can. You have the power and ability to make recovery a reality.

Bill Schneider

Building a Consumer-Centered Mental Health System

The President's New Freedom Commission on Mental Health Report (2003) states "Consumers of mental health services must stand at the center of the system of care. Consumers' needs must drive the care and services that are provided." Consumer organizations have worked diligently to assure that the voices of consumers are heard at all levels of the public mental health care system. These groups have joined together to outline core values inherent in the development of a consumer-centered system. According to the Substance Abuse and Mental Health Services Administration's *Community Integration Now!*, these values are similar to the values adopted by peer-run services. They list the following:

- **“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?
- Are people connected to natural supports?
- Are they treated fairly?
- Do they experience continuity and security?

Survey tools such as these listed provide a meaningful look at a person’s success at achieving the quality of life they desire by looking at people as a whole and whether the services they receive aid them in achieving their goals.

It is equally important to look at the system of care from a recovery viewpoint. A powerful new instrument has evolved from the “Mental Health Recovery: What Helps, What Hinders” project. The Recovery Oriented System Indicators (ROSI) survey addresses 8 specific domains within the mental health system:

- 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 of choosing services and making purchases that will help them begin or remain on the road to recovery and to develop or regain a life of meaningful, productive activity (Florida Self-Directed Care Handbook, 2006).

People at all levels of recovery are eligible for SDC. The ability to complete a Life Analysis (self-assessment) and develop a Life Action plan (treatment plan) and budget, with the assistance of a Life Coach, is the primary qualification. The FloridaSDC Program gives each participant control of the public financial resources to access mental health services that are normally directly contracted to a public community mental health provider. FloridaSDC participants can use their budgets to purchase clinical recovery services, recovery support services, and recovery enhancements. In SDC, the person is his or her own case manager.

Life Coaches orient the individual to the process involved in the program, provide referral information, advocate for the participants and promote self-advocacy, and help them to explore their personal recovery goals and prioritize and plan their budgets. Life Coaches help broaden a person's world view and consumers as Life Coaches bring a powerful perspective to the position.

A successful person-centered system incorporates the above values and assures the

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. We conducted a gospel service on the first ward we visited. One young man, whose flushed face seemed to be in constant motion, sat on the floor with his legs crossed and periodically jumped off the floor like a Mexican jumping bean. We then visited a crowded ward where motionless people stared into space, while others flailed their arms and had animated conversations with the air. Next door, a naked woman walked rapidly in endless circles. The last ward we visited seemed like a surreal scene from a horror movie. People wrapped in white straightjackets lay on the floor or sat against a white wall, blank eyes staring into another world. My mind uneasily returned to the present, along with the childhood fear that I would be committed to a "mental hospital" and never be released. I asked the counselor, "If I admit myself, can I sign myself out?" The answer was not entirely reassuring, but I knew that this was my only chance to live. The counselor told me of several hospitals, and I chose one for pastors which did not describe its program as using a 12-step model. Shame flooded my emotions. Pastors are to be examples of the abundant life of Christ, not "mental patients." I had assured others that there was no shame in seeking such help, so I asked myself, "Who do you think you are?" and I made a commitment to fully participate in the hospital's programs. I knew this would be difficult, but I did not know how difficult.

The hospital staff was compassionate and professionally competent. The first 3 days of my 3-month stay were spent taking tests. The psychiatrist, head psychologist, program administrator, social worker, primary therapist, art therapist, recreational therapist, spiritual director, medical doctor, and nutritionist interviewed me. They

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. I remained in the hospital another 5 weeks, processing the memories and learning to cope with the flashbacks. I spent 1 week in transitional care preparing to return home. My primary therapist referred me to a psychologist in my hometown and suggested that I interview counselors to find one who would meet my needs.

I quickly discovered that counselors do not like even short phone interviews, and that life “after hospital” was more difficult than life “before hospital.” I felt as if everyone could tell that I was a “mental patient,” and I felt more estranged from people than ever. I began seeing the counselor whom the hospital referred me to. He was a competent, caring professional who referred me elsewhere when necessary.

I now began the work of recovery. My psychiatrist prescribed an antipsychotic, but it made me feel so drowsy and confused that, after 1 month, he asked me to stop taking it. He also prescribed an antidepressant, which helped me resume activity. I attended a men’s therapy group; saw a trauma counselor and an art therapist; and, to my own amazement, attended 12-step groups. The work of recovery was a demanding full-time job, and 1 year after returning home, I resigned from the Salvation Army and went on Social Security Disability. I enrolled in college and earned a Bachelor of Science degree in community and human services and improved my knowledge of computer software programs. I engaged in extensive family-of-origin work and passionately pursued genealogy. This was my outpatient recovery work. My inpatient recovery work involved scheduled follow-up counseling at the Saint Barnabas Center (SBC) 1 and 2 years after my discharge.

I learned at SBC that the first step in receiving help is to ask for help. Three years after my discharge from SBC, I admitted myself to a nationally recognized psychiatric hospital that specialized in trauma care. I was not in crisis, but I continued to have intense difficulty every winter. I thought that further processing

the flashbacks might alleviate this. When I met with the psychiatrist, he insisted that I take medication, and when I declined he asserted, "This is because of your faith." I denied this, and he kept repeating his assertion. I explained that at SBC, the psychiatrist offered me medication but advised me that if I faced my pain, I could process my emotions more effectively. He replied, "Don't interject another psychiatrist between you and me." I then asked if I could check myself out. He said, "Only if I do not send you to the state hospital." Rockland State Hospital flashed in my mind, and I phoned my wife, who picked me up and drove me home. The only result of my stay was a huge bill and a renewed fear of hospitals.

I kept working on my recovery, but life kept getting harder. I isolated myself for the next 4 years, rarely leaving the house or answering the phone. Our family income was two thirds less than when I worked. We moved 8 times and to 3 different states in 11 years. I was emotionally absent from my loving wife and precious children. The guilt over not supporting them financially or emotionally was overwhelming. I strived to keep up with the housework, cooking, and family taxi service. I sometimes attended meetings at a Christian and missionary alliance church, where a few members reached out to me. They talked with me, listened to me, and invited me to take part in church activities. The elders asked me to teach an adult Sunday school class. I accepted, and when the pastor resigned, the church asked me to do the work of an intentional interim pastor. The elders and I worked together to reconcile and reorganize the church, and within 1 year we called a senior pastor. The church achieved its goals, but I realized that pastoral work was too emotionally demanding for me and that I needed to change careers. This decision, though a good one, created a void in my life, and when I did not quickly find work, life stopped again.

I admitted myself to a faith-based psychiatric hospital to be stabilized on medication, so I could continue my job search. The program took a "one treatment fits all" approach. The staff did not understand me or connect with me. Their favorite phrase, among many tired slogans, was, "If you work the program, the program works." The spiritual director identified sin as the cause of my depression and berated me for being in the hospital. I entered the hospital on a Saturday and did not see the program psychiatrist until Tuesday. He took me off the antidepressant that the on-call psychiatrist had prescribed. The old medicine took 2 days to clear my system, and the day before "my week" was up, I began taking a new antidepressant. I returned home with a huge hospital bill and dramatic side effects from the medication. I felt extremely irritable and shaky and erupted in uncharacteristic fits of anger. This was listed as a side effect of the medication, so I stopped it and went to a local psychiatrist for help. I was all talked out. I had processed my emotions. I had learned coping skills. I no longer cared why I was ill. I just wanted to find a medication that would jump-start me and help me return to work. A local psychiatrist prescribed an antidepressant that had previously helped, but this time I had an adverse reaction. He then prescribed an herbal remedy, and when I moved out of state, I kept taking the herb but did not see a psychiatrist.

My job search became more sporadic with every nonresponse or rejection, and for

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 Team (FACT). I researched FACT on the Internet, applied for the job, and I was hired. I am grateful to all who gave me the opportunity to return to work. FACT teams enable people who have histories of long or frequent psychiatric hospitalizations to live in the community. I took great satisfaction that my education, previous work experience, skills acquired while disabled, and experience with mental illness all enabled me to do this work. However, one evening, after about 3 months, with sobs I told my wife, "I cannot do this anymore." The next morning, I told my team leader the same thing. She made some adjustments to my job, which alleviated some of the stress and increased my contribution to the team. Many difficult days followed, but every day I worked, I grew stronger. I no longer

needed medication because work had become the best medication. This could not have been the starting place in my recovery, but it was a great place to be.

I attended a NAMI Peer-to-Peer Education class with several of the FACT team members. An underlying philosophy of the class is that, “We have more in common than not.” We discussed the isolation, stigma, trauma, loss, and grief common to all who experience mental illness and how the onslaught of mental illness completely disrupted our lives. Before this, I saw myself as emotionally ill and different from people with schizophrenia who were “mentally ill.” But the more we talked, the more I realized that our issues, fears, and thoughts were the same, though our diagnosis and symptoms were different. Today I often hear people with mental illness say, “I am not like other people with _____.” We do this to protect ourselves from the stigma of the pervasive stereotypes of people with mental illness.

I empathized with the devastating loneliness, isolation, and boredom that many FACT team members experienced. They were no longer confined in locked hospital wards or imprisoned behind bars, but some were prisoners in their own homes, and others were repeatedly victimized in the community. I realized that friends, productive activities, and caring, sensitive social groups are as important to recovery as therapy or medication. As a peer specialist, I could be friendly but I could not be a friend. I could transport people to groups or activities, but this was a drop of water in an ocean of need.

I worked for the FACT team for 1 year and then accepted a job as the Senior Life Coach with the FloridaSCD Program. My work with the FACT team and Salvation Army brought me into contact with people who were the most severely and persistently mentally ill. A significant minority of these people had a history of violence, an active substance abuse problem, and repeated incarcerations. This narrow experience, and media portrayals of the mentally ill, had begun to color my perceptions about who the mentally ill are and what they are like. On the other hand, most FloridaSDC participants are disabled or are unable to sustain full-time work, but very few have a history of violence or an active substance abuse problem. My work brings me into professional contact with many people with mental illness who are working in high-level positions. Many of their lives were terribly disrupted by the trauma of mental illness, but you would not know this unless they told you. The character, personality, and ability of people with mental illness are a microcosm of the human race. We have the same dreams, desires, and needs as everyone else, and like anyone with any chronic illness, we have some needs peculiar to the illness.

People with mental illness need hope to recover. Hope can transform the lives of even the most severely and persistently mentally ill. When people suffer debilitating physical injury, years of painful physical therapy may be required. Who would endure such prolonged pain if there were no possibility of recovery? Recovery is hard, takes time, and is a lifetime process. The belief that “I will recover” gives hope, and hope is like fresh water sprinkled on a wilting flower. Hope renews desire and purpose and empowers people to do the hard but rewarding work of recovery.

People with mental illness need support to recover. People in stable recovery

from mental illness almost always have someone in their life who stood by them through the years. Society's support is also needed. Support begins with respect, trust, encouragement, and patience. Support is also tangible practical assistance. Poverty, social isolation, and idleness are traumatic by themselves and exacerbate the plight of people with mental illness. If a person lies battered, bleeding, and dazed on the street, it would be unrealistic, cruel, and morally reprehensible to pass by or say, "Stop crying, you wicked lazy sloth! Pick yourself up and get on with your life." It is unrealistic, cruel, and morally reprehensible to expect people with severe and persistent mental illness to do the work of recovery without support. People with mental illness must take the risk, make the effort, and endure the pain of transforming their own lives, but society must create an environment where this can happen.

People with mental illness need the power of choice to recover. Americans take choice for granted and do not realize the power of choice. When people follow their own dreams, they find the motivation and energy to pursue them. When people set their own goals and achieve them, they have the satisfaction of knowing that it is their success and are willing to take responsibility for their failures.

Thank God that we live in a society that has a mental health care system, but there are gaping holes in this system. We need to develop new programs, revamp old ones, and adequately fund these programs, but we can never fund enough programs to meet all the needs of the mentally ill. We need families, clubs, and social groups of all kinds to include the mentally ill as part of their daily life.

The segment of society which I believe has the most to offer people with mental illness is the church of Jesus Christ. A healthy church is a Christ-centered community that provides friendship, social activities, volunteer opportunities, and beliefs that foster hope and respect. The healthy church does not need special ministries to meet the needs of the mentally ill. All it needs is a little wisdom about the needs of people with mental illness, and wisdom begins by understanding the importance and power of its own role. The segregation of different groups of people in the stew of American culture is isolating us from one another and prevents us from developing the empathy and respect that fosters mutual understanding and support. This compounds the plight of the mentally ill and is a giant obstacle to the recovery of people with mental illness. The role of the church as a loving Christ-centered community is vital to the recovery of the mentally ill.

When I wrote about my early life and experience with mental illness, my mood was dark and depressed, and my words stumbled onto the paper. When I wrote about recovery, I felt light and hopeful, and the words flowed. This portrays my journey of recovery. Sometimes I ask myself if life would have been different if someone had reached out to me in childhood, if the Air Force doctors had prescribed medication and therapy, or if The Salvation Army had helped me when I first asked for help. Sometimes I ask myself, where I would be today if my wife had not stood lovingly beside me, if I had been committed to a state hospital, if my first mental health workers had not been competent and caring professionals, or if I had not been given choices all along the way. The longer I was severely ill, the less society valued me and invested in my recovery. What would my life have been like if

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 unique path to recovery.

Spirituality and discipline work together for Sally and have provided the foundation for her life. This sense of order and oneness with a greater world is identified by many of our storytellers as a primary part of their recovery.

Recovery Through Mind Training

Early in the morning, I open my computer and load some colorful Buddhist images on the screen. I pull out my practice implements, a Tibetan bell and dorje, along with a rosary made of sandalwood. Then I ignite a stick of incense and light a red votive candle in a crystal holder. Finally, I open iTunes to a special play list that I call “Daily Practice.” These are a series of prayers and mantras recorded by Buddhist monks and practitioners, and I chant along with them for an hour or so every day. And that is the secret to my recovery from mental illness.



I first experienced madness many years ago when I was a junior in college, and it was a life-shattering experience. I became wildly psychotic and had to be carried off to a mental hospital in a straitjacket. At that time, I was hospitalized for nearly 6 months, and my psychiatrist later confided to me that he had feared that I would never return to sanity. Mental health treatment was very different in those days at the start of the 1960s. Most people who became as psychotic as I was very often wound up incarcerated for months in mental institutions, and many of them stayed there for life. At that time, Thorazine had just been introduced, and I was given massive doses of it.

Becoming mentally ill was, in a very real sense, the end of a person's life. Although I was lucky enough to get out of the hospital in 6 months, I found that I had become a non-person. I was a feeble shadow of my former self, and the future stretched ahead dully as something to dread. Everything that had meant anything to me, including most of my friends and any shred of self-respect, was gone. My college would not take me back, so I had to settle for a business secretarial course. A year or so later, I got married and tried to resume something that passed for a normal life, but I never could make it. A few months after I married, I cracked up again, and before long it became evident that whatever it was that happened to me—mania, madness, mental illness—would be an ever-present threat. It would creep up on me from behind, always a catastrophic surprise waiting in the wings.

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 children, whom I now saw only on weekends and holidays.

Doggedly I kept on going. Despite all of the breakdowns, I had maintained a certain spiritual outlook since an early age. Silent prayer and meditation had always been at the core of my faith, and at the IOL I had attended religious services every week. With that small kernel of hope, I pulled together the courage to start from scratch yet another time. I was able to set up housekeeping as a single woman in the city, and I found a clerical job at a printing company. I joined the choir in my church and did my best to be a good mother during the times I was allowed to see my daughter.

I have always tried to be a good person. During the periods between my breakdowns, I was careful to lead a good life. I fulfilled all of my duties first as a wife and mother and then as an employee and friend. I did not keep my mental illness secret, but I still conducted myself well enough that I was accepted and respected in the world around me. The monster of insanity, of course, was always looking over my shoulder. Within a year or so of getting my job in the city, I again began dealing with manic episodes and the depression that followed. Just as these experiences led to the loss of marriage and family, so my Jekyll-and-Hyde behavior shocked and frightened any new acquaintances and colleagues. I did not like to admit it, even to myself, but I knew that I had failed and damaged people that I loved. The anger and aggression that came out during my episodes turned me into a monster myself. Even worse, I had neglected my children, because the long absences caused by my hospitalizations must have seemed like abandonment to them.

In my mid 30s, I tried to start over once again by moving to the country with a new lover, a woman I had met at NOW meetings. I found a good job with a local newspaper and successfully pursued my career as a writer and editor. Here again, however, the same pattern repeated itself and I, again, struggled with episodes of madness. By this time, deinstitutionalization had made it possible to go in and out of the hospital for short stays without being trapped there, so for the most part I tried to sit out the episodes of madness at home. But the unexpected arrogance and irrationality that went along with the mania were too much for my partner, and she left me to endure the torments of my delusions alone.

It was at this time that I began to explore spiritual alternatives to the churches I had attended in the past. At the suggestion of a colleague at the newspaper, one Friday evening I drove to a Tibetan Buddhist retreat center in the next state. Over that weekend, I was introduced to a way of thinking and a spiritual practice that suddenly put everything in a new perspective. I hungrily listened to some teachings, attended meditation sessions, and purchased a handful of books to bring home with me. Buddhism had always seemed too passive for me—kind of “spacey” and irrelevant. But the first thing that I discovered as I began to study it was that it was

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 my friends in AA, and by this time whatever health insurance I had had was gone. I could no longer pay the bills in private hospitals, so my episodes of loud music and delusions were interrupted not by men in white coats but by police officers, who transported me to the state mental hospital. There, I would wander the silent halls and take my Thorazine for a week or so until I came down from the manic high and reestablished myself as a non-person just getting through life as unobtrusively as possible.

I entered a period that was to last for the next few years, when once or even twice a year, I was overtaken by a manic episode, spent a week or two in the state mental hospital, and returned to my apartment, depressed, to start all over again. This usually happened like clockwork around my birthday in August. It became difficult to hold down a job.

On one of these visits to the state hospital, I began to figure out that the peer support that had been so comforting and helpful at AA meetings could also be put to use here. Instead of curling up in a fetal position on the couch in the dayroom, I began talking with other patients and listening to them the way that people had listened to me at AA meetings. As I did this, I remembered something that a lama had told me when I was staying at the Buddhist monastery. He had encouraged me to accept the spiritual insights of my madness and to use what I had learned from it to help other people. Now this advice seemed to click into place.

This time, when I stumbled back into my apartment with its sink overflowing with dirty dishes and phonograph records strewn on the floor, I was ready to transform myself once again. In a kind of prayer, I called on the presences that had helped me in the past—at the IOL, I had assumed it was God and His angels—and asked them to guide me. This led me to join a new organization in town composed of families of people like me and a few of the people who had mental illnesses themselves.

This time, I was onto something. I became the leader of a small support group of the other people struggling with mental illness—my peers—and this group grew to be one of the first peer-run organizations of its kind in the country. I realized that I had found my vocation in life. From that point onward, my mission was to organize and advocate for people who, as one advocate put it, “experience mood swings, fear, voices, and visions.”

As I did this work, my disposition brightened and expanded, and along with that my attraction to the Buddhist point of view returned. I still sang in an Episcopal choir, but I also joined a small Dharma study group in the area. The lama who had advised me to help others was right, because as I learned compassion, I also learned to believe in myself—I, who had for years secretly believed myself to be a non-person. It turned out that recovery from mental illness would become the rallying

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 a healthy diet, exercise regularly, and try to reduce stress to a minimum. Most importantly, I pray for my full recovery every day. I thank God for His power and hand in my life every moment.

I joined NAMI in 2001, and I became a facilitator and member of its Board of Directors. Because of my participation as a facilitator, I recovered wisely because I listened to other consumers' symptoms and issues every Saturday. By helping other consumers, I helped myself recover faster and with dignity. That was when I totally overcame my illness and completely changed my life along with my participation at church. I became aware of my symptoms and the causes of my illness. By facilitating these groups, I realized that my problems were minimal compared with being homeless, drug and alcohol addicted, and having psychotic symptoms. I was always able to have a normal conversation, even though I would sleep most of the time. I spent 1½ years sleeping and drooling every 5 minutes. My jaws shook and I looked drained and tired most of the time.

Five years have passed, and I am still on the Board of Directors of Miami Behavioral Health Center, where I help make decisions for my community. Also, I proudly work for Magellan Health Services as the consumer recovery manager for Area 11. I was referred to Magellan because NAMI recommended me for the position. I am blessed; I can help 63,000 Medicaid recipients in Miami-Dade and Monroe counties. I have the opportunity to do outreach for the community at a massive level and offer health services.

My life took a complete turn when I met Jesus Christ, who healed me and is still working on my illness, and He gave me the opportunity to help others with their illnesses. I am ecstatic about my new job and career in which I help our community at a higher level on a daily basis. I am glad I am where I am. I wish all mentally ill consumers would recover and provide service to their communities, especially those who are at home disabled and are trapped in their illness.

I bless God for my recovery; I will keep on helping and getting involved in support for recovery. This is my legacy in life.

Gina Basile

Supportive Housing

Housing is the number one need of ex-patients (consumer/survivors). When I speak about the housing needs of those who have been classified mentally ill, I do not mean shelters, group homes, supervised apartments, and other so-called solutions. Most ex-patients want real homes, rooms, or apartments in which they can live permanently, either alone or with someone of their choice.

Judy Chamberlin (1988)

When we talk about independent living, we're not talking about leaving people alone to suffer with no help. We're talking about having freedom to make choices; to choose whom and what to be interdependent with; to choose when we need help, how it is to be provided and by whom....in short, we're talking about empowerment, we're talking about independent living, with supports and services that enable us crazy folks to make a success of independent living.

Howie the Harp, in Carling (1995)

In looking at methods for helping people to fully integrate into the life of the community around them, one of the first things that must be present is a safe, decent, affordable, and private place to live. Group homes, assisted living facilities, and programs that tie services to living arrangements fail to support the principles of self-determination and integration and continue the cycle of learned helplessness and segregation. People at nearly all levels of recovery can, with supports and meaningful choices, learn to live in the community and establish rewarding connections to the world around them.

Here are some of the underlying values of supportive housing:

- No one should be forced into supportive housing.
- But when people have real choices with the supports and tools to make those choices most people choose to live independently in the community.
- Choices need to be provided in ways that people understand the implications and consequences of those choices.
- The right to make choices must be supported even when staff members do not agree with those choices.
- "Successful supportive housing reflects a delicate balance between choice and safety that is respectful of personal preferences" (*State of Florida Guidelines to Supportive Housing for Persons with Mental Illness, 2003*).
- Choices should include not only where a person lives but also regarding roommates, use of legal substances, and participation in services.

Providers of supportive housing services should offer a wide choice of available, affordable housing. Affordable often means that rental assistance needs to be available to meet the individuals' needs. Housing choices should be close to public transportation and local businesses.

Without the safety and support of having affordable, decent housing in the community, many consumers end up homeless, in institutions, or in jail.

According to this excerpt from *Community Integration Now!* (2002),

Despite having access to federal funding, local and state governments do not do enough to help people with disabilities secure affordable, accessible, and appropriate housing. Although a small percentage of Department of Housing and Urban Development (HUD) funding goes to programs specifically for people with disabilities, it is not enough, and people with disabilities lose out on other HUD-funded houses for reasons including:

- **Income.** Local and state governments often choose to use HUD funding to create housing for working-class families, and people who rely on disability cannot afford this housing.
- **Age.** Local housing agencies can designate HUD-funded housing as “elderly only,” thus excluding younger people with disabilities.

State legislatures should allocate an adequate amount of money to cover the housing needs of people leaving institutions and other people with disabilities who do not have affordable, accessible, and appropriate housing. A significant amount of public funds should be allocated to local rental and homeowner assistance programs.

Although programs such as Shelter Plus Care tie housing to services and thus can be a major blockade to real independence, they can offer a range of rental assistance models:

- Tenant-based rental assistance—people select their own rental housing and have the ability to move.
- Sponsor-based rental assistance—people live in housing owned or leased by a sponsoring nonprofit agency.
- Project-based rental assistance—specific housing units are set aside for people who qualify for the program.
- Single Room Occupancy (SRO)—a particular building is developed into single rooms for people who have been homeless.

Community Integration Now! (2002)

Supportive housing models can be far more effective by meeting an individual’s housing needs first and providing access to support services as the person chooses. Homeless individuals with psychiatric disabilities and co-occurring substance addictions are our most vulnerable population. This is particularly evident among those living on the streets in urban environments. They are the least likely group to gain access to housing programs (Tsemberis & Eisenberg, 2000).

The Housing First model has been particularly successful in working with this particular group of people. Using this model, Pathways to Housing in New York City began a supported housing program designed to meet the needs of homeless individuals who live on the streets and who have severe psychiatric disabilities and co-occurring disorders. The program is designed for individuals who have been unable or unwilling to find housing through traditional programs. It was founded on the belief that housing is a basic human right for all individuals, with or without disabilities. The program provides clients with housing first and then

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 grant 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.

I was a small-town boy with large dreams and considerable intelligence. When my brain couldn't figure something out, my confidence and resourcefulness took over. As I look back, I realize that some of the risks I took early on in my life, especially during a very successful and lucrative marketing career with companies such as Miller Brewing Company and Citi Investing Corp. along with my many start-up corporations such as Beverage Group International, were probably the first concrete indications of my mental illness.

In fact, I began experiencing extreme highs and lows, as well as delusional thinking, when I was about 11 years old. But the mood cycles were at such long intervals that I never saw a pattern. Then in the fall of 1990, I had a bout with depression that brought me to my knees. In 2 months' time, I lost everything: my family, my business partners, my fortune, and my will to live. The story of my depression at this time became more than a bout in that it manifested itself as both an internal and external war. Because I had not yet lost all of my financial resources, I checked into a motel on Pensacola Beach and began to see my therapist 3 times a week. This process, along with prescribed medication, should have been enough to pull me free, or so I thought in my delusions, but the symptoms became worse. Although I went through the motions of recovery, I still had not made a full commitment. I left the beach and moved back in with my family and continued to run many of the companies, making outrageous decisions, driving my partners and my family further away. Nothing was working, and I would go on feeding frenzies and eat everything in the house. I started actively hallucinating and even attempted suicide when my family was gone during the day. I thought of suicide every day, but I wanted it to be clean and wanted to do no harm to my wife and children.

Finally, in a last-ditch effort, my wife asked me if I would meet my therapist at 6 on Friday evening. I was totally unaware of what was to come next. I had gotten to the point in my life where my wife and my therapist were the only two people I trusted, and I did everything they requested. At one point my therapist, a Christian, requested that I list every sin that I could remember from the earliest point of my life up to the current time. The purpose of this act was that we were going to pray at the end of the exercise, burn the extensive list, and all would be forgiven. The list was never burned because we never reached the end of this exercise, and it would later come back to harm my relationship with my wife and family in the most severe way possible. However, as I stated earlier, I completely trusted them and agreed to this Friday evening meeting. When I arrived at the appointment, they informed me that we were going to take a drive and discuss some of the issues that had now become barriers to my recovery. We went directly to the Baker Act receiving unit at Lakeview Center in Pensacola, where I was informed that they had a bed reserved for me.

Terror filled my heart and desperation clouded my senses at the scene that lay before me. Several policemen were bringing in people who were obviously under the influence of street drugs and were acting with resistance, and sometimes, violence. As the paperwork was being completed for my admission, I looked through the window in the door to the receiving unit and was terrified at what I witnessed. Please understand that until this point, I had no experience with the

mental health system at all, and everything I heard and saw was completely alien to my being. One of the things that my father had taught me was that “a man never shows his weakness or fear.” In fact, my nickname is “Grizzly.” But this time, I lost all of my inhibitions and began to sob, beg, and plead that they not leave me alone in this place. I was pleading not so much for the safety of my body, since loss of life at this point seemed like a beautiful respite, but because of the fear of possibly being locked up forever with no control over even the most basic human needs. I became so pitiful at one point that my actions caught the attention of the two policemen and the admission staff person, and I knew that I risked being locked up. My wife and my therapist listened to my pleas, and it was only when I pledged to voluntarily admit myself later the next week that they acquiesced and took me home. **Even for a stepper, some steps are simply too big and, in this case, too scary.** My dad would have been ashamed.

That following week, I remember my wife driving me around on the grounds of West Florida Community Care Center, the local psychiatric hospital in my area. Our intent was to keep my promise and admit myself on a voluntary basis. Once again, terror filled my heart as we began the slow drive to what I would later find out to be the Baker Act receiving unit, a fenced in area with a Sheriff’s car parked inside and the gate closed. We drove around the facility several times with my wife demanding that we park at the admission area and that I walk through the door. My doctor and my family had given me the option of becoming a patient at the facility on a voluntary basis or to be admitted involuntarily under the Baker Act of Florida. This first visit seemed so threatening and ominous, and yet I knew it was where I belonged. After this visit, I made one simple request: that I be allowed to visit my mother and father on our family farm in Mississippi to confirm if actual events had taken place in my childhood or if they were perceptions of a child’s wild imagination.

This confrontational meeting between my mother and father and me proved successful, and the many years of dreams and nightmares were finally confirmed as a reality. I won’t go into detail at this point about this frightening yet freeing experience because it is a totally different story and will be recalled at a later time in a book about the story of my life. Now that actual events had been confirmed, I felt strong enough to face my darkest fears, and within 2 weeks of my first visit, I checked into the hospital. “No big step for a stepper.”

More than 2 million Americans have bipolar disorder. It is characterized by episodic mood cycles that are specific to each individual and include at least one manic episode. A manic episode is an abnormally elevated or irritable mood, not related to substance abuse or a medical condition, which lasts at least 1 week and includes disturbances in behavior and thinking, such as impulsiveness and feelings of invincibility that result in significant problems with life adjustment. For example, during certain manic episodes I tried to run four different corporations at one time. Although these companies had the common thread of marketing and national distribution of consumer products, they were miles apart in their stages of development and the amount of stress and attention required to keep them operating and successful. At one point, after a meeting with a major corporation

in Indianapolis, two of my partners and I were driving back to Pittsburg when my anxiety level reached a heightened point, and I pulled the car over on the side of the freeway got out and began to run. I had been an athlete all of my life. Track and field was my specialty, and when I ran I felt free, but this time it wasn't for recreation; it was out of desperation. My past had reared its ugly head and was once again chasing me in the wakeful hours of the daily sun. My partners and close friends became used to this eccentric behavior and saw it as a sign of the uniqueness of my persona. The illness made me feel that nothing could prevent me from achieving my goals, no matter how far-fetched they seemed to others. In fact, the riskier the investment and the more far-fetched the effort, the flow of adrenaline to my system became the very elixir or addiction of my life. "No big step for a stepper."

I sought treatment at West Florida Community Care Center, a state psychiatric hospital managed by Lakeview Center, Inc., located in Milton, Florida. It was during my stay that I first met Dr. Victor Francis, my psychiatrist, who would later on become my friend. I had met with Dr. Francis and my social worker a couple of times before my third and most enlightening meeting with him. It was during this meeting that Victor diagnosed me with bipolar disorder, a brain disease that could be treated and brought under control with a holistic approach of medication, group and one-on-one therapy, and improved physical health. He began to explain this disease in detail and was able to match the mania and depression with certain behaviors and decisions that had controlled my life up to this point. The long road to recovery began here, where I remained in treatment for 9 months. Some days I made progress; other days I went backward. I describe this process as "the path to discovery," a path that is seldom the shortest distance between 2 points. It's more like a switchback on the side of a mountain. At times, it can be frustrating and you can feel so defeated, as though you're not getting anywhere. But then you realize that, just as the zigzagging path of a switchback takes longer than charging straight up the slope, the zigzagging path to discovery is also more gradual, allowing you to learn things about yourself and about managing your illness that you never would have known. You inhale these discoveries until they become a part of you. Instead of being breathless as you get close to the summit, you have reserves and resources to fall back on. You become a more resilient person.

"No big step for a stepper." An extrovert by nature, I realized that I enjoyed, and seemed to have a knack for, teaching others who were struggling along the same path. As I moved through the continuum of care provided through Lakeview Center's treatment services, from hospital inpatient to the less intense residential program known as The Lodges, I began taking on volunteer roles including dorm parent and peer counselor. Interacting and becoming friends with clients, staff, and administrators, I was recognized and respected as an articulate spokesman for those with mental illness. I became a mentor and voice for many individuals who had begun to lose hope in their own recovery, and made frequent trips to Tallahassee, testifying before the legislature on issues of importance to those in need of mental health services. My path to discovery had now allowed me to walk on the road to recovery. In fact, my active participation and contribution to addressing mental health issues became my therapy and empowered me to push forward

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 Person's 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

supportive network of peers, family and friends, I learned to manage my chronic condition. And, in my new career with the state, I am behind the plow once again, on the cutting edge of Florida's growing consumer movement, working with the Florida Certification Board to recognize individuals with mental illness who receive special training to be employed as Certified Recovery Peer Specialists.

"Recovery is real and achievable." "I am living proof that there is reason for hope for anyone with a mental illness." As our country moves towards data-proved programs called Evidenced-Based Practices, I believe if ever we have to deal with barriers even from within the movement of consumer advocates, we should stand proud and repeat that the best determining factor that supports those Evidence-Based Practices is ITE; "I'm the evidence". In other words, "no big step for a stepper."

Threads That Connect

One Person's Approach on How to Deal With Mental Illness

I have the right to be happy. I did not choose to have a mental illness. It was thrust on me or inherited by me through no fault of my own. I am not a diagnosis but a whole person, created by my genetic makeup, environment, and experiences. This illness is not indicative of some moral weakness, spiritual retardation, or emotional disenchantment. Although my illness may be composed of some of these "flaws" in my life, I believe that my total being is worth more and stronger than the sum of these "flaws."

I believe that thoughts go through the brain at a high rate of speed. These thoughts are both positive and negative (i.e., beneficial or harmful) to me. I believe that I can train my brain to capture those thoughts that can be both beneficial and healthy to my life. This training can be done through prayer, meditation, or simple belief. This training will allow me to "cast a mental net" deep into the seat of my brain to bring into my life those thoughts that will help me live a happier life and leave behind those thoughts that have caused me great harm and suffering in the past.

I believe that people get back what they give out. I can either drink the last of the water in the jug and thus survive or I can use the water in that jug to prime the pump connected to the well of life and bring forth enough water to drink, cleanse myself, refresh myself and finally refill the jug again for the next person to use to prime the pump. This act of faith and hope allows me to go beyond mere survival and represents the beginning of a fulfilled and happier life. In fact, I believe this simple act of leaving the "water" of hope behind for my brothers and sisters will make me stronger and wiser than those who have had to suffer with my illness.

I believe that the road to better mental health is paved with the knowledge of education. This education process must first start with me before I look to others for answers. This is my body, I must listen to it, this is my brain, I must study it, these are my thoughts, I must acknowledge them before I can change and improve them. Finally, and most importantly, this is my life, only I can live it. The way I choose to live it is determined by me and me alone. My educational process begins and ends here within me and me alone. My family, friends, doctors, nurses, counselors, and anyone else who is actively involved in trying to educate me are

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, Copyright May 1994

Elvira Sears, like many of us, has experienced the loss of her career, material possessions, self-confidence, and the support of family and friends. But, through years of hard work and hope, she has found a new meaning and mission for her life. Elvira reminds us of the importance for each of us to have a safe, affordable place of our own to begin that journey. She describes the satisfaction found in helping others and experiencing their successes, and she explains how having stable, effective services in the community and people who believe in you makes the process possible. Finally, she tells us how important the support and companionship of her peers and her participation in local drop-in centers has been.

I thought my life was just beginning. I'd finished college a few years earlier and was working on a genetics research project. Then, symptoms started appearing, and my life came to a standstill. I had to be reminded what to do when I woke up... to brush my teeth, to wash up. The man I was living with at the time started staying home with me, and we both sought help through his employee assistance provider. The psychologist there suggested I go to one of the area hospitals. This was my first of about six psychiatric hospitalizations.

My diagnosis was schizophrenia. After the hospitalization, I continued with therapy and medication. I continued trying to work, but I couldn't keep a job very long. I tried clerical work, proofreading, and waiting tables. I even tried substitute teaching (I had gotten a teaching degree as "something to fall back on"), but my illness caused me to treat the students inappropriately.

One of my psychiatrists suggested I try to get a civil service job. At first I was reluctant, because I thought I'd be working with people like me. Eventually, I started working with people with mental retardation. A provision in the job allowed me to take off 12 weeks if I worked 1250 hours. That leave helped considerably, and I kept that job for about 11 years.

In 1998, I had a very bad experience with the day treatment program. At this program in New York, someone committed suicide. I had to leave after that, and I went home to Florida, thinking my life was over. I was cut off from my medication, and I constantly thought about death and dying.

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 call your own and sometimes serves as an alternative to being incarcerated or sleeping on a park bench. The worry of being moved from place to place no longer exists. The importance of housing in the community is a major accomplishment for not only me but for others around me. Just the thought of having “Your Own Place” gives a person a certain sense of being; it awakens something deep inside, which lights up the spirit.

In addition to my work, I volunteer for the Mental Health Association and facilitate a Schizophrenics Anonymous support group. Also, to help others I became a certified presenter in the NAMI In Our Own Voice program. The presentation is available to make the public more aware of mental illness. Helping others not only helps them but also helps me. I think being busy and having something to do is important. I still spend some time at home, but I try to get out every day.

When a person is ill, it’s important to have the support of family and friends. I stayed away from my family for 22 years thinking that if I came home, they’d lock me away in an asylum, but to my surprise, they were very supportive. Of course, some are less supportive than others. Some people say, “There’s nothing wrong with you. You’re just spoiled.” There are always going to be people who won’t accept mental illness. A mental illness isn’t like a physical handicap because you can’t see it.

Drop-in centers are very important places for consumers to go as an alternative to isolating themselves at home. Presently I attend and am an active member at three drop-in-centers including 9 Muses Art Center, in Lauderhill, Florida; REBELS Drop-in-Center in Hollywood; and the Personal Empowerment Education and Recreation (PEER) Center in Oakland Park. Before leaving New York, to help in my recovery, I also attended drop-in-centers there.

I used to think I was doomed. I used to talk about how I would prepare for my funeral. Looking back on that now, I feel marvelous. As long as there’s life, there’s hope.

Elvira Sears

Daina Gold began her struggle with mental illness as a young high school girl far away from home. Like many of us, it was years before she was able to manage her symptoms and build her career. But medications alone did not protect her from a devastating relapse. Through self-help, support of friends and family, and traditional mental health services, Daina now lives a rich, fulfilling life. She is in recovery.

Encouragement for the Bipolar Soul is her story.

In 1972, I was a high-school freshman, skinny, with long untamed hair. I was a decent kid who made above-average grades, a happy girl with lots of personality. I was relaxed in my trendy bellbottom pants and white leather clogs. I was just 16, starting to flex my decision-making muscles, to find my way away from my mother's strong will.

In the middle of my first year in high school, my extraordinarily zealous mother, without warning, put me on a plane bound for a strict boarding school near Washington, DC. I was not being sufficiently obedient to her religious rules. She sought out a decidedly conservative school and sent me away in the hopes that I would conform to the extreme rules that have governed her life.

As it turned out, that boarding school's rules were indeed exacting, but the faculty was anything but severe. With their loving guidance and direction, I thrived. I was happy. My cheerfulness and above-average academic talent won me lots of friends, a place in the traveling choir, and a B+ grade average. I loved my teachers and I worked to get good grades.

Up until I was 19, my life was "regular." Then the brainpower I had counted on to run my life was taken from me. Without rhyme or reason, I gradually fell into a depression that lasted most of my senior year in high school. I remember feeling disconnected from everything and everyone. All my thoughts sank with dullness and dreariness. Although I wouldn't know its name for a while, the onset of bipolar disorder was making its way into the circuits of my brain's communication systems. I had ceased to be "normal."

The subtle change in my mood was almost invisible at first. However, the effects materialized soon enough. In the "normal years," I had been active and enjoyed all my meals without a second thought. Now I ate mindlessly. This can be seen clearly by glancing through my yearbooks. A close look at the photos reveals a vacant-eyed chubby girl in the space where a slender bright-eyed girl had always been.

My grade point average suffered severely. I graduated because my first years in high school were successful. I went home to live with my dad. Later that summer, the manic part of manic depression introduced itself to me, but not before my first bout with depression had its way with me.

My normally strong analytical skills did not serve me. My awareness of myself evaporated and I experienced myself as an empty shell. My mood was not an emotional tantrum. Something stronger than my ability to manage my life overtook my thoughts; a diluted capacity for joy or pleasure left me with ideas of ending my life.

My dad, a brilliant physician, was raising 3 children alone. He had gone to court and won full custody of us from my imbalanced mother. When I came home after graduation, still 19, he was in for a surprise. His previously happy, well-adjusted daughter arrived home a different person.

I stayed in bed all day. I didn't do anything; I didn't dust, vacuum, or clean a single toilet. I was unable to move the mountain of despair off my chest. I was barely feeling, and my feelings informed me I was a failure without hope.

I can only imagine how frustrated my dad must have been, not knowing what to do with me, a stranger in his household. Unfortunately, back in 1976, manic-depressive disease was not yet on the radar screen for doctors outside of psychiatry.

After 12 years of highly regulated private education, I didn't know what I was getting into at Michigan State University, academic home to 43,000 students, all enjoying adult freedoms. The freedom was breathtaking; I enjoyed every moment. Completely oblivious to how my action annoyed others, I stayed up day and night, jabbering to anyone who would listen. I was manic.

My mood was euphoric, yet I was aggravated when others could not keep up with me. My ability to concentrate had disappeared, so I talked as fast as I could. Sleeping became optional. From somewhere inside me, an increased sense of self-esteem burst into grandiose delusions of academic brilliance. I was out of my mind, and, one by one, everyone I knew stopped interacting with me.

However, I didn't even realize that I was in trouble until my dad received a copy of my grades. As it turned out, I flunked all first-term classes except for one: tennis, in which I managed to earn a passing grade of C+. That C+ helps me laugh as I look back on the beginning of my journey through madness.

My father (the doctor) was hurt, confused, and angry. His daughter, in whom he had been well pleased, was no longer pleasing. My appalling failure was repulsive to my dad, for whom achievement was paramount. He commanded me to leave his home. Actually, what he said was—and this I remember word for word—“I cannot have this kind of failure living under my roof.” He meant it. Scrambling for alternatives, I quickly telephoned relatives.

My aunt was enthusiastic for me to come to her Texas home. I was her first-born niece, and she was confident that my being with her would straighten me out and get me back on the path to success. After a few days of excitement, depression crept in where the mania had been. I slept in for several days in a row, without offering to help with any chores. She didn't know what to do with me despite her advanced nursing degrees and top-notch communications skills. A few weeks later, I became aware that the warm welcome had cooled off. Therefore, I took another bus, this time back to Denver.

Now, at age 20, I was alone in a black bubble of hopelessness. I decided there was only one place to go, to my mother's house in Denver. I am not sure why she allowed me to come. Her undiagnosed mental illness had flared up during the years. The shock therapy she received in the late 1960s to alleviate post-divorce depression did not help. She refused further treatment, since doctors and prescription medication went against her doctrines. Her unhappiness, having been dramatically

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

better. Soon I engaged in all the patient activities. I volunteered my thoughts in group therapy. I was doing so well that they released me within just a few weeks. Although the doctors observed me, they offered no diagnosis and no recommended treatment.

I slipped through the system undetected. How did they overlook my disorder? Bipolar disorder is different from other diseases because it does not follow a neat path of a beginning, middle, and final closure. It just keeps ending and beginning without a scheduled pattern. If one thinks of the disorder as a series of rounded spikes and dips on a graph, there are places on the graph where the disease registers as “normal.” My temporary normality probably threw the doctors off course, and within weeks, my first severe manic episode threw me into the air like the rockets that push the shuttle away from the safety of the earth.

If you have ever had a severe manic episode, this clinical description will bring back memories, both awesome and destructive. If your experience with mania is anything like mine, you will remember the pleasure as vividly as the destruction. If you do not have this disease, it may be normal for you to look at people with untreated mania as ridiculous, illogical, arrogant, pushy, or lazy. It may become unbearable for you to be in their vicinity.

Not long after I left the sanitarium, I got a place to live with yet another of my grandparents’ friends and was asked to leave when I would not honor curfew and keep my room clean, and I repeatedly woke up my landlady at odd hours to talk incessantly. I drained her with my constant illogical chatter, clutter, and coming home in the wee hours of the morning.

I found and lost a job. I was not dignified when Alex, the assistant manager, took me out for a drink, drove me to his house for my first sexual occurrence of going all the way, and fired me the next morning. This was my introduction to an activity that would keep me occupied for the next several months.

I developed an addiction to sex, not realizing that an increased sex drive was a part of my disease, and that I could be quite entertaining and not at all repelling if I was in a man’s company only for a short while. I cannot remember how many men there were; except for Alex, I don’t remember any of their names.

The depression snuck back in. I quit my job. I contemplated suicide again. I purposely made a choice to fly to California, get drunk, and drown in the Pacific Ocean. I left a note and all my clothes and got on the plane.

Obviously, my plans changed. I didn’t have enough money to get to the ocean, so I checked into a grungy hotel tucked in the shadows just behind the power center of Los Angeles. The hotel manager let me stay longer than I had money to pay. He took his currency from me in another fashion, and in my state of mind, I didn’t resist. My manic craving for interaction and excitement interfered with my ability to discern danger. I left my door slightly ajar “Looking for Mr. Goodbar.” That is, until I woke up one day, no longer depressed.

I was lucky. I called my dad. It had been 2 years since he put me on the bus for Texas. He seemed happy to hear from me and flew me home. Nevertheless, once

again, we couldn't seem to get along. Of course, neither of us knew that the mania was taking over. Neither of us knew how to make it better.

I moved in with an old girlfriend whose rich parents fed us both. My friend was crazier than I was. Her drug habits kept her up all night, so neither of us slept; we went from bar to bar looking for trouble.

I finally hit bottom. The early afternoon sun was shining through the steel bars guarding my cell. I was sketching a mural on that same wall with a #2 pencil. I arranged, and rearranged, my cigarettes on the floor in artistic abstract shapes, and I was irrational. I was singing and dancing. I talked loudly to my new neighbors in the jail cells adjacent to mine. It was early 1979 when I found myself in the city jail in downtown Lansing, Michigan.

Earlier that day, I had been singing at the top of my voice when I passed a police officer. He rewarded me with a ticket for speeding. Was this incident enough to land me in jail? No. However, having a second unpaid ticket from the same officer who had ticketed me for speeding 3 months earlier and a warrant out for my arrest was.

To me, my day in jail was one of exuberance and excitement. My dad's experience was not the same as mine. As he stood at the reception counter, he could hear me singing "Amazing Grace" at the top of my lungs from my cell. I was giving a concert for all the men in the cells around me. I got applause from them and commitment papers from the state.

Within an hour, I was out of jail and into a police car, on my way to Ypsilanti State Hospital. I tried to serenade my captors. I sang, "We Are the Champions" by Queen repeatedly, but neither of them was impressed.

Did I feel good about being diagnosed? Did I feel better after I started taking the medications? A whole lot better. I felt so good about knowing my diagnosis, that for 23 years I lived without "being kicked around" by the symptoms of untreated manic depression.

After leaving the hospital, my life took on a brand new quality. My dad and I developed a new relationship. This time, when he asked me to find my own place, it wasn't because he was kicking me out. At the age of 24, it was time for me to leave the family nest and find my way in the world.

I moved into a co-op just off the campus of Michigan State University in 1980. Now chemically balanced with the help of prescribed drugs, I was an upbeat, responsible member of the co-op community. I loved my job as a bartender in a greasy-spoon grill. I took classes at the community college, where my mind embraced learning with joy.

I found a boyfriend. We got married. Our marriage lasted 14 years, during which time I graduated from Rutgers University and began a career as a corporate trainer. The reasons for our divorce did not relate directly to my disease.

Years passed.

I was blessed to find another good man. We married in 2001. He was attracted to my happy personality and he wooed me with the strength of his character.

By the time I turned 46, I was a well-paid consultant for a large corporation headquartered near New York City. I had it all—a home on the ocean in Florida, a flashy sports car, many close friends, speaking engagements, and a dear husband who loved me like a rock (and, thankfully, still does!).

However, I did not respect my brain chemistry condition. I couldn't be bothered with doctors because most of the doctors I encountered were uninterested prescription-pushers. I found a way to get around the system. I found a way to buy lithium wholesale. I disregarded my need for blood tests and stayed in denial by taking my lithium tablets as though they were simply vitamins.

My 23 years of denial backfired. In 2003, my chemically balanced life tipped over. My marriage, job, and purpose for being alive got tangled in chaos, complete with dissatisfaction, arrogance, boredom, and a general dread. My midlife crisis was about to blow in with hurricane strength. I made an awful choice.

I was 46 years old. I was happy. My consulting practice was profitable. As a work-relationships coach, I was receiving a retainer fee of \$10,000 every month. This feast lasted 7 years. Along the way, I let my smaller clients go and invested all of my talents into one huge corporation.

I loved having lots of money. I did all the right things: I hired a CPA, tithed, and invested. I loved shopping without looking at the price tag. Then, as always in business, things changed. My huge client reorganized, and the new leaders demanded a different type of coaching service. I was terrified. I hadn't prepared myself to compete on the open market. Seven years had passed, and I didn't have a network of helpful people lined up to help me through a transition. My self-esteem disappeared; my self-confidence took a beating. At 46, I felt old, used up, and as if I were out of options. I wasn't depressed in the bipolar sense. I was still taking lithium every day. I just felt lost.

My friends, usually in awe of my ability to coach and counsel, started giving me advice. "Take this vitamin." "Take these herbs." "Go see my acupuncturist." "What you need is electromagnetic body work." I kept reading that I could heal myself from every condition, if only I learned to think the positive thoughts and take the perfect blend of organic food and natural supplements. I started believing that I was powerful enough to rid myself of a permanent condition. I found myself perching over the abyss of insanity, and I lost my balance.

In 2003, after decades of taking lithium as easily as I brushed my teeth, a false belief lodged in my mind. A nasty little idea informed me that I wasn't interesting or exciting enough, and that I needed to be more. While I don't know exactly how this idea overthrew 23 years of functionality, I decided on my own that I would become creative and more appealing without my medication.

My psychiatrist at the time was one of my least favorite people. I had selected him from my company health insurance book and called for an appointment based on his convenient location. He didn't listen. He wasn't interested in me beyond

his invoice. However, I didn't really care. I was still buying lithium wholesale, so I didn't have to see him more than once a year for blood tests. It's fair to say that I did not have a support team in place. It's also fair to say that I did not take my disorder seriously.

For 2-1/2 months, really believing that I was smarter than the entire psychiatric profession, I slowly reduced my lithium. Slowly but surely, now stripped of the drug that tames the brain's synapses, mania reared its ugly head. I ceased to be the caring, insightful, fun-loving woman my inner circle of friends knew me to be. I ceased listening to the wisdom of my family. I became erratic and inappropriate. My family begged me, even tried to trick me into getting help. I couldn't discern my need for medical attention. I was flying high on faulty brain circuitry.

Against all attempts at intervention, I got on a plane to visit my major East Coast clients. I was unrecognizable due to my mania. I was curt to the support staff, who were used to seeing me as a well-respected consultant. My first client of the day was my last client ever. When I jabbered on about end-of-the-world prophecies, he asked me to report to Human Resources because he felt something was wrong with me. I was ushered out the door.

The drama escalated. Instead of going home, I traveled in my rented Cadillac to the middle of Manhattan and checked into a 5-star hotel. My mood, thoughts, and self-esteem were at the height of excess and delusion.

On August 14, 2003, my mood escalated to a full-blown manic episode. That afternoon, the electrical grid that supported New York City failed, creating a citywide blackout. Imagine someone completely manic colliding into the thousands of people pouring into the street of Manhattan, due to a citywide power outage. I thought I was the reincarnation of John the Baptist's sister, and that Jesus would be returning, landing in Central Park at midnight!

There were only a few people in the park, and, as you know, Jesus did not appear. At 2 a.m., after trying in vain to find shelter, I went to the only safe place open, the police station, where I was convinced to admit myself to a hospital. My new home was behind locked doors in the mental illness ward, where I stayed for 6 weeks. I received acts of kindness but I had no health insurance to pay a counselor; I was on my own between mandatory group activities. Doped up with lots of mood stabilizers for weeks on end, I paced the halls, which was my main activity. I wore out a pair of red sandals walking around and around the fluorescent-lit hallways.

Six weeks after arriving at the hospital, I needed to be sent home. However, despite a complete potpourri of medications to bring me down, I was still too manic to mail. My doctor tested me to see if I was safe to travel in an airplane. She injected me with a powerful antipsychotic drug and asked me to stay put in a chair. However, I couldn't cooperate. I just couldn't sit still. A loyal friend from college, who was willing to risk my presence in her home, let me stay with her family while I continued my treatment in an outpatient clinic.

Finally, I flew home. I wasn't manic anymore. However, even after weeks of hospitalization and getting enough medications to keep me subdued, my brain chemistry now ricocheted between light and heavy depression. For months and

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

of Holy Land tours 7 years after that. We separated for a year and a half while I worked for the regional manager of Finnair, then reconciled and moved to Fort Lauderdale in 1970, where we bought a house in advance of moving his office down. That never happened, so he mostly came down here to entertain clients. He lived in New York; my son and I lived in Florida.

My symptoms began in my mid-30s and I began searching for relief in self-help books, seminars, and courses. I had become a daily drinker (evenings) as were most of my friends. At 40 in the late 1970s, I decided to end my marriage. As a settlement, Pano agreed to finance an adult fitness center using rings and trapeze patterned after one I had belonged to in New York City. A month after opening, having spent half the money for startup, my husband refused to give me the balance promised and I had to close the fitness center. One of the students offered to lend me the money to continue, but I already felt my confidence sliding and was afraid I couldn't pay her back.

In retrospect, I had been hypomanic during this period (the five lovers I was juggling, who ranged in age from 18 to 52, was one sign!), and the ending to my dream sent me into my first paralyzing depression. I could arise from my bed only with the greatest of effort, driving to Boca Raton to pick up my son from boarding school on weekends, but he had to fend for himself when we got home. I stopped eating and obsessed about suicide. I had never been like this, so my husband paid to fly my mother down from West Virginia on the first of several "rescue missions." When school ended, my son went to Fire Island and Greece with his father while my mother took me to West Virginia and the Greenbrier Clinic for a thorough physical. I was found healthy but depressed and was started on a tricyclic antidepressant.

Back home in Fort Lauderdale, I started seeing a psychiatrist. None of the medications we tried worked. Then my husband offered me a job working in his European office. His ulterior motive was to keep our 15-year-old son in school in Switzerland, where he had put him, against his will, at the end of the summer. Hope restored, my mood escalated into hypomania, and I flew to Geneva. On the plane, I stopped taking my meds and started drinking. In my Geneva hotel room, I called friends and family in Fort Lauderdale, New York, London, Athens, and Rome with no thought to the triple cost of long-distance rates in hotels! I rented a car and drove to my son's school in Versoix. He was not happy there, but was stuck with no home or mother to return to.

On to Rome for a couple of weeks and then to Athens to stay with my mother-in-law while escorting tour groups from airports to hotels and vice versa, I had always used and kept my executive planners, so later I could tell that my manias lasted an average of 4 months followed by longer periods of depression.

In an Athens bar, I met some American men from the National Can Company and took up with one of them. He, his friends, and I went to Mykonos for a holiday weekend where I was surprised to see my ex-husband with his current girlfriend and then my mother. It hadn't dawned on me they were there to try to put a lid on my behavior. Among other things, I had been dancing atop the bar at one of the clubs the night before.

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 I was told by my sponsors to have “no mood or mind-altering drugs.” That was just what I wanted to hear, and I stopped seeing the shrink. The mood swings continued, but in my “creative periods” I started new groups at Gateway, a Saturday night dance at the 101 Club and a Memorial Day weekend 4th and 5th Step Marathon at my house, where I also let people from AA stay until I realized they were running up my phone bill and eating all my food. In 1980, I spent a month at the Beachcomber (substance abuse rehabilitation) in Delray.

Later, my mother arrived on another rescue mission and took me to a psychiatrist at a community mental health center. We noticed that the psychiatrist’s fingernails

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

to West Virginia and, on returning to Florida, repaired my seawall and insulated my windows, all of which I couldn't return to a store when coming to my senses. I also "loaned" a guy I didn't know \$9,000 of the \$20,000 I said I would put in as his partner by writing checks against my credit cards. He claimed to be installing burglar alarms on boats, which sounded like a great idea to me (another manic reaction). He had the nerve to threaten to sue me for the balance! Of course, I never saw him or the \$9,000 again.

I went to work for Jordan Marsh department stores so I would have some medical insurance and started with the round of psychiatrists again. One tried Tofranil. Nothing. Another psychiatrist put me on lithium and Wellbutrin, and they worked!!! All of these medications put weight on me, which I find almost impossible to lose, but it's a trade-off for my stability. My son, who was living in New York, was very supportive and sent me about \$500 a month for several months to help with the bills and allow us to keep the house, which was debt-free. It took a long time and continuing stability for my son to be convinced that he could trust me again.

My best friend found a local depressive/manic-depressive support group, where I got most of my information about the help available. There I learned that compliance with my medication and acceptance of my illness was the beginning of my recovery. Fifteen years later, I facilitate that group at Atlantic Shores Psychiatric Hospital's auditorium to make sure it's still there for others who need it as much as I did. I suggest that people find (or start) support groups to be with peers who know what they're going through, who will encourage them, and who will share information and skills to cope with their illness. They help deal with family members as well, and they are free of charge. I also read all the books I could find. Patty Duke's *A Brilliant Madness* was most helpful.

I learned about the PEER Center, a drop-in center, and began to volunteer, setting up their mailing list. I discovered I was eligible for schooling through vocational rehabilitation. Although I had a college degree, I took computer and bookkeeping courses, being unsure if I could learn or retain anything (I could). Through volunteering, I learned of a job opening at the MHA of Broward County. They were the PEER Center's sponsor for their first year, helping them get their 501(c)(3), set up a board, and accomplish all the things necessary to be on their own.

I got the job at MHA as administrative assistant in 1993, and one of my first assignments was to compile a handbook of mental health services and supports targeted to the homeless and newly diagnosed. The back cover of this book, *Connections*, lists famous people with mental illness under the heading "People with Mental Illness Enrich Our Lives." We are now updating the 13th edition. My boss, Anita Godfrey, is the best advocate I have ever met and is my mentor. She felt that my illness was an asset to the position. I have been working steadily for 14 years for the same organization, a record for me, and I have never missed work because of my mental illness.

In addition to being a member of the Florida Peer Network, I'm a member of the Adult Mental Health Committee and the Alcohol, Drug Abuse, and Mental

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 donated to their residences as a consumer-to-consumer project.

9Muses votes every year on becoming independent and leaving MHA, but no one ever wants the hassle of payroll, audits, etc., leaving us free to concentrate on our art and music — the fun stuff. Whenever you're in the Fort Lauderdale area, come and visit with us!

Janice Eberly Anastasato

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 its 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, including supervision, training, and transportation.” A fully implemented supported employment program helps to find real jobs for people in real work environments. Instead of changing the nature of the work, it concentrates on providing the supports necessary for people to succeed in that work. Wehman and Kregel (1985) suggest that most supported employment programs should include four functions: job acquisition, job site training, ongoing monitoring, and follow-up. Anthony and Blanch (1989) describe several principles that appear critical to successful employment for people with disabilities. These include substantial

involvement of the people themselves in selecting work options based on their interests and abilities; focusing the assessment process on people's individual work goals; providing for a more lengthy pre-employment phase if needed; assuring that there are a range of jobs with advancement potential; anticipating problems with stigma, and therefore assuring that people do not have to identify themselves as "psychiatrically disabled" in the workplace if they choose not to; providing training in resume writing, interviewing, and other skill areas; planning family members' involvement with a sensitivity to the autonomy of each consumer; focusing on the application and use of skills, rather than only on their acquisition; and coordinating supports during nonworking hours (Carling, 1995).

Supported employment offers another opportunity for peer-run programs to provide important services. People in recovery have a unique perspective when it comes to understanding the barriers to successful employment. There are several peer-run employment agencies and supported employment services across the country. Another innovative idea in the employment arena is Supported Self-Employment. In these programs, people with disabilities are provided help to start and operate small businesses that provide them with a flexible means of earning income, as well as supporting a sense of personal accomplishment (Community Integration Now! 2002).

Stories of Survival & Recovery *The Creative Spirit*

Greg Umlauf is a dedicated and creative songwriter and musician who has a bachelors degree in communications from Florida Atlantic University. He is an integral part of a large and loving family, one of 10 children and uncle to 17 nieces and nephews. Through his strong faith and belief in God, Greg has survived more than 30 years of mental illness. He credits the support of people who believed in him and his creative spirit with much of his success.

Severed in Two – Surviving Bipolar Mood Disorder is his story.

This story is about how my life has been severed in two. Some psychiatrists and counselors disagree that a traumatic car accident could have triggered my first breakdown, which happened a month and a half after the accident. Some say that it is just about the age that mental illness sets in. It doesn't matter to me anymore, as I have learned to deal with schizoaffective bipolar illness. I am stable now, but I can never say I will never be hospitalized again. I have probably been hospitalized more than 20 times in these past 30 years.

As I've said, my life has been severed in two. My first 17 years were a Camelot. In my earlier years, I have memories of playing sports with my dad and 6 other brothers and cousins, and with my baby sister, when we'd let her. Then I got heavily involved in music, playing many instruments in band and piano lessons. I was a very happy child. I lived in the Detroit area (Dearborn), and I remember listening to Motown music and other top 40 songs, as well as Tiger baseball on the radio as we were falling asleep. I had my own lawn service, not just for the money,

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 Avenue 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, graffiti, smell of urine, and quiet rooms with fenced-in windows with plenty of scratch marks.

The doctors misdiagnosed me at first, thinking I had schizophrenia. They shot me up with Thorazine and Haldol. I became a zombie. Two times on this medication, I've had allergic reactions where I thought I was being electrocuted. My back arched all the way from my head to my feet. Another incident I remember about the psych

unit was that I was lying face down in my bed, and a big guy came in my room, managed to get my pants down, and tried to rape me. The nurses caught him in time, but he was gone after that.

Then I finally went home after 3 weeks, but I was a walking zombie. I couldn't even put my socks on because my hands would break out in a sweat. I remember my mom trying to get me to exercise and telling me to just walk down to the mailbox and back. That was such an effort.

In January, the doctors agreed to take me off all medication, and I had a rebound like you wouldn't believe. My girlfriend would cut a lot of classes so we could go to the woods to make out. I started to get better on the trombone again and ended up graduating with my class.

That summer of 1976, I took classes at Santa Fe Community College in Gainesville and got back to practicing my trombone for the fall, where I would be marching with the Gator band and playing in the Jazz band. I graduated from Santa Fe in a year and a half because I went summers.

I started at the University of Florida in music education for 1 semester. Stress got to me, so I dropped out. I thought about joining the Air Force and even took the exam, but I couldn't find a career I wanted. I was lost again.

My girlfriend's mother said that we couldn't see each other anymore. That was, by far, the most devastating event of my love life. As the song goes, "the first cut is the deepest." Well, I know I never recovered from that one because I'm 48 now and still have never been married.

After all of the 20 or so hospitalizations I've experienced, I always had to start my life over from scratch: more schooling, new jobs, more manias, and a lot more clinical depressions, which I call Hell.

Soon afterward, I was hospitalized again but for more serious risks. I was in a hit-and-run car accident. My parents saw the damage on my car, but I was so far gone I couldn't explain it, so they called the police. Again, I was back in the hospital, but the old 4th floor was torn down and a temporary psych unit was put up until a big psych unit in Gainesville was built.

Again, I left the hospital depressed as could be, but now the doctors had the proper diagnosis. This was in 1978, and I was put on lithium. Because lithium is a salt, it made me thirsty all the time, and the most disturbing side effect was diarrhea for 13 years. Then the lithium started to affect my kidneys, so the doctors had to find an alternate medication for me.

Everybody feels depressed once in a while, some more than others. But clinical depression is a whole different game. It's paralyzing. You can't see the light at the end of the tunnel. I am so grateful to God to have not experienced it in approximately 10 years. Now if I can just get my mania under control, which I have these past 2 years.

Until actually writing this story down on paper, I seem to forget what horrifying things I've experienced in my life, and it is the silence before the act of actually committing to your own death that is chilling. You've never felt so alone or judged,

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 world 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 first visit and the continued tax money that has gone into improving mental health care. I owe my life to almost everyone in this country for their taxes; the doctors, nurses, and medical researchers; and to my loving family and friends who have come and gone.

The trailer is only a long-gone symbol of how far we have come in the knowledge and care for the mentally ill in this country and in other countries as well.

Now, in Gainesville we have a Crisis Stabilizations Unit, a Drug and Alcohol Rehabilitation Facility, and many large hospitals including Vista Pavilion for the care of the mentally ill. We have residential apartments for people with all different levels of abilities. In all my 30 years of this type of mental illness, I've never met a doctor, nurse, or therapist who didn't try with the best of their ability to help me get back on my feet. Throughout these 30 years, I would land on my feet and get back to the task of living a stable life. So, in essence, I've got to give myself credit, too, for always trying to catch up with society.

January 19, 2004, was when my mania started up again. I had gone 7 years without being hospitalized, except for a brief stay after the September 11, 2001, (9/11) attacks. As 2004 progressed, I got worse. I was hospitalized 3 times that year, but the most devastating visit was the last one where I stayed 3 weeks and missed my parents' 55th wedding anniversary and family reunion. I was mostly bitter.

I was finally released on July 15th, and the FACT Team did so much for me. As my first FACT doctor said, "We are a psychiatric hospital without walls." Not only did the FACT Team help get me out of the regular hospital, but they also split the cost with me to put me up in a motel until my apartment was ready. They then put the deposit down and totally furnished my apartment with brand-new furniture. On top of that, the FACT Team provides monthly doctors' appointments, weekly therapy, student nurses, and a full-time nurse. I have taken full advantage of everything they have offered me. When they noticed how heavy I was getting, they bought me a scale and an exercise bike and, later, a blood pressure kit to monitor my hypertension. I thank God every night for this team of wonderful and dedicated people.

Now for the part I really wanted to get to—the present. I am now on summer vacation, as I have been working as a dishwasher at the local Catholic elementary school. I love my job and the crew of people I work with. I have the best apartment in the whole complex, which is the closest to the pool with a beautiful view outside my bay window.

I am again on a weight loss program, this time with a registered dietician, and my psychiatrist is watching the blood levels for my medications very carefully. Since October 14, 2005, I have lost 38 pounds and I am controlling my appetite much better.

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

Asariah Umar Asante is a skilled technician and artist who hears voices. He has lived with his illness for most of his life. As he grew older, he began to self-medicate to escape the stressors in his life. He has dealt with his addictions and managed his illness by building a system of support for himself. He credits Mary Ellen Copeland's Wellness and Recovery Action Plan (WRAP) with giving him the tools he needs to maintain his recovery and along the way he has become a WRAP facilitator to help others.

As a young child during the 1960s, along with my two younger sisters, I learned early that I was different from other children. My sisters played dollhouse and pretended to be parents to their dolls. I, on the other hand, played with G.I. Joe action figures. The difference was that I talked with my figures, and, instead of them becoming part of my world, I became a part of theirs. As I grew older, maybe about 9, I began to play around other children but not really with them. When others invited me to play either hide-and-seek or football, I excelled beyond my stage of development. In sandlot football, I'd play with drug dealers or gangs from the neighborhood, but in my quiet world were voices that seemed to advise me to pass by the world around me. It was difficult for me to read and comprehend or solve math questions. When I thought I had the answer, I would forget what I was focused on. The voices began to get louder and stayed with me longer. It seemed like I was never able to pay attention to the world around me. One day, my mother was doing my sister's hair for school and she sent me to get hairpins. I, instead, went to get clothespins from the bathroom windowsill, and while talking to the voices, I slipped on the wet tub edge and hit my head on the soap dish mounted on the wall. I don't know how many stitches it took to sew my head up, but this was the first incident with voices that almost killed me. After that, I could not sleep more than 4 hours a night. Every night, I would stare at the ceiling, imagining that I was with the people in my head.

At the age of 12, I began to fantasize that I was in professional sports. Neighbors bought me NFL pro football electrical games. I guess it was because I played by myself most of the time. My parents would buy me a football to play with, but my imaginary friends wouldn't allow me to share it with others. When I reached junior high school, I knew I was a pretty good artist for my age, as well as athletically inclined. I could run for miles talking to the voices. I could draw anything my brain could comprehend and even creatures never seen before except in my head. Every night, I would sleep for about 4 hours and spend the rest of the night sitting on the window sill watching the people of the night come and go. I wanted so badly to go outside to feel the night air on my face. Instead, I pressed my face against the window screen and watched the stars as my imaginary friends got louder and began, in my mind, to take on physical appearances. Many days, my mother would spank my hands to get me to pay attention. I would go into a defensive mode, and tears would roll down my cheeks as I blamed my voices.

At age 18, I went into the Marines. I thought that if we got away (my voices and I), I would be a true hero, a war hero. However, during the entry test the psychiatrist and another professional soldier convinced me not to just be a soldier but an aviation technician for helicopters and jet engines. I guess taking apart discarded

radios and scrapped bicycles allowed me to look at anything in pieces and know immediately how they went back together. I realized that I was a master technician who heard voices, a good artist who lived in the worlds he created.

But people, I've learned later, disturbed my relationship with my voices. The stress of anger, fear, grief, abandonment, and resentment, all of life's stressors, caused me problems as an adult. I began to self-medicate and hang out with other marines who made substance abuse a daily activity. Then I discovered that these negative thoughts were pressed on me by the voices. Now I have learned after an extensive criminal history, hospitalizations, and periods of chronic relapses, that self-medication had to stop and that I needed to find a self-help support network that works for me. I knew that Narcotics Anonymous (NA) was the only program that could save me from self-medication or active addiction.

So I established a history with a medication regimen and a long-standing relationship with my doctors. I also experienced day treatment programs that assisted me with coping and life skills. I was convinced through therapy that I needed to separate from my second wife and begin to take care of myself. I enrolled in school, graduated from the University of Miami as an HIV/AIDS and Addiction Specialist, did my internship, and was hired in a behavioral health program as a mental health technician and case manager.

Then I stopped my medication, experienced voices, and had trouble with other stressors. I lost my job, relapsed, and became homeless. After another year of active addiction, I decided I would come back to recovery, yet I knew something would be missing. You need a support network for behavioral health, a network of friends and associates that is solely available for mental health consumers. Most health care professionals would refer me to self-help groups or networks in which I could not talk about the voices in my head. I had to keep the topic on weight loss, AA, NA, Overeaters, gambling, etc.

Today, through Mary Ellen Copeland's WRAP network and program of recovery to wellness, I am familiar with all of the material suggested in her books which help people like me. For the last year, my life has changed tremendously. I can talk to those in my network about my illness as well as about other unhealthy activities. I feel that WRAP was designed specifically for me. Thank you all who helped in designing, providing and maintaining such a wonderful program in the state of Florida. Now I can add "WRAP facilitator" to my educational credentials.

God Bless,

Asariah Umar Asante

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 run by professionals. At peer-run centers, consumers are not patients or clients but are owners and staff, and, first and foremost, they are people. Drop-in centers should be many things to many people. People use drop-in centers for a wide range of needs. Some come for safety and refuge, some for a quiet place to relax and contemplate, others to meet friends (old and new), for information and education, advocacy, jobs, and often to help themselves by helping others. A drop-in center

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, which 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

it was; if somebody had a folder I thought it was about me. If I went shopping, I knew that the women in the office were talking about me. If I were to return some product or something, they would think it was some sort of plot. They would think I was plotting against them, so now they were going to plot against me.

I believe that the trigger was situational. I don't mean situational as in some small way, I mean situational as in a terrible life trauma. I experienced physical abuse in a bad marriage. When you are trapped in something like that for so many years, it becomes very intimidating. When you are thrown against the wall and your life is threatened repeatedly, it really triggers something. If some illness exists deep down inside you, that kind of experience will bring it out. Those types of situations are the breeding ground for bringing to the surface some condition you may have. I wasn't severely abnormal growing up. I've always been somewhat performance oriented, enthusiastic, and energetic, at worst, hyperactive, but I wasn't ill, delusional, or suicidal growing up.

I don't know which came first. My husband was highly controlling, to the point that I didn't see my family for 10 years, but why didn't I cry out? Why didn't I do something? Some of that was the dynamic of that marriage. I was so angry! Some of it was situational, but some of it was just out of control. I was so severely angry, I hated him. I put glass in his sandwich. Another time I tried to poison him.

The funny thing was that the worse I got, the more I believed my delusions. I believed what I was thinking. That's very intriguing because you would believe such odd thoughts (like the paranoia with the folders and stuff) would make you notice how absurd your thinking is. On the contrary, the more delusional it was, the more I believed it. That's a funny thing to me.

I couldn't get out. I wanted out. I'm not talking about out of the marriage; I'm talking about out of my mind. It was agony. I didn't disagree with my thinking, but I knew I was in agony. I was always negative, never positive. I was always upset. There were no moments where I would feel better. There were only moments where I would feel even worse. I figured if I could just get medicine I could get out of it, and I couldn't get it because I didn't have the insurance. I wanted the medication because I felt so bad, not because I believed anything was untrue. I always believed everything was true that I was thinking, but I knew I felt bad. Not depressed. This was a more active rage and severe agitation. Agitation was a word I used all the time. It wasn't even the hopelessness of giving up; it was the hopelessness of thinking I couldn't get out. It was just bad.

I was hospitalized at a community mental health center crisis stabilization unit twice, then another time in a community hospital psychiatric ward. I stayed there for a couple of weeks. One time I was trying to get away from my husband. I was at the courthouse, and everything looked different. The light was really, really bright and I couldn't even see where the ground was. My perception was off, my sight was off. I was in some sort of a state. I was just talking with this woman, and she kept looking at me as if I were crazy, so who knows what I was doing. Anyway, shortly thereafter, the authorities came and took me away, and I still don't remember the precipitating factors.

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 how they provided my needs for me when I eventually left my husband and I had nothing. And I mean nothing, and they came in and established stable housing for me. The best thing they ever gave me was a vacuum cleaner. How I loved that vacuum!

All I needed was a lifeline, a life preserver. The FACT team was a life preserver of pleasantness. They lifted me up. They believed in me and were positive towards me. I'm surprised that there is so much value in that, but there is.

They gave me their respect, and I don't even know why, but they did. I didn't do a damn thing to deserve it. I mean, I looked atrocious, I acted poorly, I wasn't accomplishing anything, and they were championing me. They said, "You can do it" and "You're doing great." It was the attitude that you're going to make it, and here are the things that you need, and here is what are we are going to do next. They were cheerleaders.

They saw something in me that I didn't see. I didn't even think there was anything there. That, above all, is what got me through. I notice now, all the time, throughout the day, how a therapist helps. Like, this is how you approach life, and these are the tools. Now that helps, but at that time, I just needed someone to go to the store with me and be nice.

My mother, who lived in a mobile home park, said, "We're going to get the first and last months' rent, and security deposit, and put you into this mobile home park." It was wonderful being next to my mother. Then the FACT team would show up with all this stuff. They put a bed in. They went with me to a thrift store and bought a couch for me. They came with arms full of dishes and bedding and I had a house. I was free and I had a house! I got a job as soon as I could. I was a cashier. I could handle that; it was appropriate for where I was in my life. They got me a bicycle so I could get back and forth to work. They kept coming with the medicine. They fixed the poverty situation. My mother helped me manage my money, and they put in place the necessary items such as food, clothes, and shelter that we all need.

There is an essential component of "I" in recovery. If there is no "I," it doesn't work. This is a 2-man team, and if 1 man works and the other doesn't, then it doesn't work. It was up to me to take the reins and take the medicine and work to change my life. I used my support system. I worked to be a part of this society and to affect my life positively. If I do what I'm supposed to do, it will work. All the essential components will rise up, and that is what happened. I rose up. I wish I had some better way of saying it.

I don't feel as if I have really clearly explained it. I really feel as if I went from moderate insanity to being a productive, fulfilled, happy citizen. I went from agony to happiness. My biggest trauma in this whole thing was my husband. When FACT and I rebuilt my life, my situation with my husband became so small. My traumas became so small.

I wanted to go to a shelter for abused women for counseling. That was one of the essential components. The best counseling is being with others who are like you. The difference for me was being with those other women. I saw those people rebuilding their lives. I was rebuilding mine and I was in the same boat with them. It was empowering! I gained something there. Now those are part of the tools I have with me.

I know I speak much about life circumstances, but these circumstances work against those who are mentally ill because they don't have the where with all to rise above it. Look what it took to get out of poverty, champion me when I couldn't think straight, give me medication to make the delusions disappear, and support me in the work that it takes to rebuild a life. It's been years and I've been on the FACT Team for 4 years.

As a Peer Specialist, I am part of the team, so I get to distribute the very medicine that helped me. I help with housing, nursing care, life care, all of the components that we provide on the FACT Team. I'm part of the day-to-day function of the team. Also, I'm a Peer, so, of course, my slant is on unity, rebuilding lives, and

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. Going back, when I was a young girl, I had a very happy, loving childhood. I am the youngest of 6 children and have a twin brother. My parents were wonderful, supporting, encouraging, and loving people. The problem was that although I was in a happy home, I wasn't always happy. Athletics have always been a part of my life. I played 3 varsity sports all 4 years of high school. I excelled in softball and was honored to be an All State Player in 1977. I went on to college and continued to play. My academic record was fair for the first 2 years; however, by my junior year, I was on probation. I had to quit school, although I was voted Most Valuable Player on the college softball team.

I don't write this to brag or be boastful. I write to say that although things were happy on the outside, I was depressed and unhappy on the inside. At that time, I just didn't realize how depressed I was. When I left school, I went to work for my father at his restaurant. It was at this point that I started to use drugs and alcohol. I loved how they made me feel, how they got me out of myself.

For the next 7 years, my alcohol and drug habit continued and got progressively worse. By the time I was 28 years old, I was completely beat up mentally and physically. I checked myself into a detoxification unit. I was depressed and desperate in my mind and, at that point, in my body, too. I had exhausted my family and friends, so when a new friend wanted to move to the West Coast, I went. I thought my life would be better.

It was fun at first, but then I started to get depressed again. I realize now that stress is the number one trigger in my life. It can be good stress or bad stress; it doesn't matter because the outcome is still the same. Stress is a killer.

I had a major breakdown in 1990 that lasted approximately 1 year. I was very ill and never saw it coming and didn't comprehend what was happening to me. I hadn't slept in 3 weeks and had eaten very little. I lost 40 pounds in 3 months. As the days went by, I never even thought about going to see a doctor; to this day, I don't know why. My family and friends didn't know what was wrong either. They prayed that it would be temporary.

I was completely hopeless and helpless and I proceeded to cut my wrists. Later, I realized that I didn't want to die; I just wanted to get help. I was hallucinating

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 losing 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 stayed with my husband for so long (17 years). I would wake up in the middle of the night and get scared. It scared me so bad that I still have bad dreams about it. Now I call the crisis line or I have people from the NAMI Cares Group that I will call. I'm able to talk with them. Once I find out that they are doing well, I find that I'm not doing that badly.

I'm co-facilitating the Cares Group now. It has really helped my confidence. The other facilitators are certified through NAMI. They are going to try to get me certified, too, so that I can run the groups myself.

I also have some other things that help me. I have my support group, my friends, and my self-confidence. I have my 7-year-old son and a 20-year-old son who back me up all the time. They are wonderful kids. The support my 20-year-old gives me, I can't express my feelings about it enough because he's seen me, he's been there. He saw me when I beat on myself and was hard on myself. Now he is just so supportive, he's wonderful. I can call him any time of the day. I call him when I'm feeling a little down, and he gets me all perked back up again.

I write in my journals; I have two of them: one for all the negative things that come to mind, and the other for all the positive things. I write all the tasks I need to be doing for the day, even if it is just reading a book for a little bit of a time so I can feel calm enough to read. Mostly I'll do work. I started a garden out here. I also do all the things around the house, especially the laundry. I'm very compulsive about that, so there is never any dirty laundry. So those things are very positive.

I finally got Medicare. That's a very wonderful thing that just started happening. Also, my psych doctor is really good. If I call her and tell her that I'm having a bad time, or that I have really bad anxiety or something like that, she'll up my meds a little bit. It helps me for that day and gets me out of the depression and of feeling really bad.

There are also things that I do for fun. This weekend, my boyfriend and I took my son, Jason, fishing and swimming. We rode the four-wheeler. I just met Bill, who has paranoid schizophrenia, a couple of weeks ago. We seem to be hitting it off pretty

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 difference.

My parents are so supportive of me. If I'm having a bad day or something like that nature, they don't pound me about it or anything. They just ask if I'm okay and if there is anything they can do. My son will come home from school and give me a kiss, and I will get to feeling really great! It's those little things. I go to his school for every function, every little thing he does there. That's what I do for fun, and it helps me a great deal.

I am looking for a new therapist; my doctor is going to help me find one. Every now and then I call my old therapist down in Stuart, and she always helps me out. She backs me up and is really happy that I'm doing well.

Having these people who believe in me is really important. I can see that it is real, that I've touched their lives. Even in the bad times in my life, I'm a good person and I've tried to be the best I could be. It's really nice to finally believe that I am helping people and that these people like to be around me. I'm not a threat to them, I'm not a bad person, and I don't need to stay in my shell anymore.

I have learned much about my illness through NAMI and through books and friends. I've learned that I really have done a good job of helping myself. although I wasn't always taking my medications, but the drugs I'm taking now really do seem to help.

I would like to be involved in the Consumer Network. I'd like to be involved in all kinds of things when it comes to helping other people with mental illness. I want to be a part of that.

The best advice I can give to someone who is just starting to deal with their illness is to realize that you are a good person, and don't lose your love for yourself. Other people have mental illness; you're not alone. If you think it is just you, then you're going to hate yourself. Just love and understand yourself, try really hard to understand the illness, and get involved. I thank God every day.

My future looks wonderful for me. Maybe even a few years from now, I can even hold a part-time job. I know I can't now and that's okay but maybe a few years from now. I would like to work in a restaurant and be with people. It has been 4 years since I have worked, and working helps me a great deal. It gives me more faith in myself and more confidence. I can step back and say that I've had a good day and look at all that I have accomplished. Just the little things in life are big accomplishments for people who have mental illness.

Karen Gaines

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 Award.

Like many people working towards recovery, Sandra has identified several positive things in her life that have helped her on the journey. She talks about friendship, family, having someone who believes in you, respect, safety, medications, therapy, meaningful work, having a safe place to live and the basic necessities, recognition, laughter, and, above all, her spirituality. Each person needs these things to live a satisfying life filled with joy and promise.

Hello, my name is Sandra McQueen-Baker and I want to share my own personal recovery story. It is my belief that to go forward, I must personally go backward. This story begins with a young girl who at about 7 years old experienced the separation of her father and mother. This opened up the door that my mother had to go to work. When she was a stay-at-home mom, I always thought I had a

“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

known because someone had taken it away from me. I never told my mother what happened to me in that house on 59th Street. I was always afraid that if I ever opened my mouth that my mother would die.

After my mother passed away, I went to the house that I shared with the man I was living with. I went inside the house and did not come back outside for 2 years. I could not walk past my front door. When company would come to the house, I would hide in the room by the side of the dresser. I would rock myself; I would cry, I would shake and I would bathe myself. I remember I would bathe in the morning, afternoon, and at night. I would bathe throughout the days trying to rid myself of the people who had molested me. I thought that if I just took a bath and washed myself clean, they would go away, but they didn't. So I would just sit in the corner by the dresser and rock and rock. I was reminded that my mother was a spiritual woman and I thought, "I know He has something for me to do." "There was no way I could have been born and not have a reason to still be here." But I would hide behind the dresser. I remember my husband said to me one day, "Listen, baby, you can be as crazy as you want to be, but I'm sick of you and this water bill." Our water bill was extremely high. I remember I would sneak and bathe while he was away. And as I would talk to God, I would hear my mother talking too. I asked, "What am I here for? What can I do? I'm so tired." I would just rock and rock. But I would say continuously that God has something for me to do; I know He has something for me to do.

One day, one of my dearest friends stopped over to see and said to me, "Sandra, there's a center down the street from you. Why don't you go there to get some help?" I said to my friend, "No, those people are crazy down there, I can't go there!" My friend said, "What do you think you are? You're hiding in the house, afraid to come outside, peeping behind the curtains." My husband tried his best to talk to me. My dad tried, too. Everybody tried, even my mother when she was alive, tried to talk to me. I just wouldn't hear any of it. One day the light bulb came on that maybe there really was something wrong with me.

I had the support systems, a husband, and my family who loved me, but there was a part of me that felt like I couldn't go to them. So I was left to myself, but there was a spark, a light, something deep down inside of me that said that I was here for a reason. I had something I could hold on to. "Don't die because you have something to do." But I was tired and tired of being in that corner. I was tired of rocking and tired of feeling ashamed. I was tired of feeling dirty, guilty, and sad. Finally my friend said that she would go with me if I made the appointment. I lied to her on several occasions that I had made the appointment when I didn't. I was so afraid. She was asking me to go outside; she was asking me to get help. I wasn't even quite sure what I needed help for. I was also tired though. So I finally did make the appointment because she pestered me to. That's what supportive people do, they won't take no for an answer when they know you need help.

I went to the community mental health center in Miami, Florida. I made the appointment, was assessed, and was assigned to group therapy. I was taking my medications and I hated them because the medication caused me to be sleeping

all the time, or always slobbering. I would sleep, sleep, sleep. My medication had to be changed a number of times. I kept seeking help from the Lord. It seemed as if He helped everyone else, why won't He help me? I kept taking my medications and sometimes throwing it away or hiding it because I was tired of being always asleep. I was diligent in attending my group therapy sessions and the individual sessions with my psychiatrist. I finally identified that spark that was sitting in there that I had something that I could offer. I could tell others about my experience and what it felt like to be asleep, to be doing drugs and running from the police. People would listen to something I had to say because they would know it is real. It is so ironic because this was from a voice that was afraid to speak.

My progress was so impressive that I was eventually offered a position through my case manager. I applied for and was given supportive housing at the time because I needed to get away from everything. I just grabbed my children, left my husband, and went into supported housing. I needed to get some clarity. I just needed peace. I was still trying to take the medications and in between throwing them away and taking them. My girlfriend came to me again and said, "Why don't you get your GED?" She said I should go over to the high school and sign up for adult classes. She reminded me that I was so smart in school I should just go over and do it? I was still afraid. It's not easy to walk outside when you are afraid and you've been inside so long.

My family tried the best they could to help me. Everybody was trying to help me. My husband said to me, "Even if I have to sit in the class with you I'll sit there, I'll help you because you can do this." I knew that I was smart and would be able to do it, but he didn't know the strength it took to walk out that door and to sit in that classroom. He just didn't understand that I was afraid. It wasn't the voices of schizophrenia but negative self-talk that said I will never be any good because of my past, and "how dare you think you could ever be something!" I don't know, it could have been the voice of schizophrenia. I was then rediagnosed with major depression because I was always depressed. I was sad because I was fighting an unseen enemy, and I didn't know what to do. The only thing I thought I had was Jesus, my spirituality, my peace. I would read the Bible and He would say to me that He would never leave me but, in reality, I felt so very alone. After my first test, my teacher told me I did such a wonderful job and then said, "Why are you in my class? Go take your GED and go on and make a life for yourself." Then, after all the worrying, I took the GED and PASSED.

Again, my friend came knocking on my door, my husband and all of the people who supported were right there. At that time I didn't know they were my support I just thought they were pests. She said, "Okay, Sandra, now you need to go to college. You can't stay home, you need to get out and go to college." My husband said that whatever it took, he would help me. I remember thinking he was too nice to me, and I wasn't used to this; I was used to ugly. But, I did prevail and went to school.

I was so afraid sitting in those little desks. I remember gripping the desk so hard I could see the palm print of it in my hand. I returned the next day and I can remember lifting my hands up to the Heavens and saying, "Okay, Jesus, you said you'd never leave me." I kept pursuing and kept going to school yet still being so afraid..

My next news was that of my aunt calling me to say that she had gotten very ill. She asked me to come to the hospital. Now this lady was like my best, best, she was the sister that I never had. She was my guardian angel; she was my best friend. When she told me she was in the hospital, I remember putting my shoes on and running down the street to the hospital because my friend needed me. She told me that she had HIV/AIDS and that she was going to die. She was crying and I was crying. I had no knowledge of HIV/AIDS. I just knew she was going to be dead the next day. I knew it was a serious illness with her being in and out of the hospital. In addition, she had to take care of her mother (my grandmother), who was in the final stages of Alzheimer's. The challenge of trying to take care of herself and my grandmother then fell on me. I had to take care of my grandmother, battle a mental illness that I was still not really sure I had, dealing with the agoraphobia, going to college, and dealing with life. Every day I woke up, I had to decide whether I was going to live or die that day.

Over the course of a few months, I had to drop out of college. I had to be a little more proactive in taking care of my aunt because she was dying. The HIV/AIDS was progressing rapidly, and I had to take care of my grandmother and my aunt's son and also try to deal with my own stuff. I was breaking down yet again because I was ill equipped to deal with her dying, my grandmother's illness, work, and rearing my own children. I know I was blessed to have those children because they were always right there with me. They didn't understand why I couldn't go outside or why I couldn't go to their games sometimes, and they didn't understand why I couldn't go to the school like other parents, but they were right there. That's all I can say. I love them passionately and thank them so much, including my husband, for standing there with me.

Once I attended one of my group therapy sessions. I was so frazzled and out of it that the therapist suggested that she would assist me in finding a place for my grandmother, a suitable nice, private place where my grandmother could thrive and be all right. I didn't have to give her the care that I could not give her because of the Alzheimer's. At approximately that same time, my aunt died.

It is my belief that without spirituality, there is nothing. I know I wouldn't have made it without it. Without the medications that I needed but was afraid to take, I couldn't have made it. Without the therapy that was necessary, I couldn't have made it. While sitting at my house one day, my case manager said that she had observed that many people from the group were calling me, asking my advice and my opinion about different things, wanting to know how I felt about different things. I would reply, and each time she visited, she noticed that I was on the phone answering and solving these problems. She finally said, "Sandra, there is a job opening as a peer counselor. Why don't you fill out the application?" I applied for the position but didn't get the job. Someone much more qualified did. I was okay about it because I really didn't want to come out of the house anyway. My case manager was persistent and about a year or two later told me of a place called a Drop-in Center, where a peer counselor position was open. She told me that she knew I could do the job and I would work in that same trailer so she would be there. The Center was with the Locktown Community Service Team.

I went in afraid because the agoraphobia was still there. I went in feeling unqualified and with low self-esteem, but I went in. I was so blessed that she was giving me a ride to work and at the end of the day I would linger around so she could give me a ride home. This worked for maybe a year, from 1996 until sometime in 1997. I can honestly say that I did well on the job. I'm proud of the work I've accomplished. Working with consumers and being active all made me feel as if I belonged somewhere. On the other hand, I was dealing with the grief of my aunt and working with my grandmother. I was also dealing with trying to be a wife to my husband and being a mother to my children, who I felt deserved a better mother. However, I could only play the cards I was dealt.

My grandmother soon passed away. I was coming out of the depression over my aunt but was beginning to surrender to depression because of my grandmother's situation. I was given deeper dosages of medications to level off and get up, but one evening I was home lying on the bed and I fell asleep — and this is not a dream — I woke up and felt the heaviness of grief lifting itself from me. It was as if my grandmother were saying goodbye. No, I was not hallucinating, and no, it was not schizophrenia. I could feel that my grandmother was saying that it was okay, "I'm going on and it's okay." I returned to work and shortly thereafter began my work at the Drop-in Center. In January, I was offered the job permanently. I felt so good about that; I felt that I belonged somewhere. I thought I could make a difference, that my life does mean something. Oh wow, it felt so good!

I remember that my husband, who is a roofer, had an accident and both his hands were very badly burned; that same week, my son was in a severe car crash in which someone had died and my son was hurt and distraught. I stayed home to take care of my husband. I had this new job and I was excited. Three weeks after these mishaps, a severe tornado hit near my home. It tore up much of the Mental Health Center and part of the trailer in which the center operated. The trailer was uninhabitable. I remember picking up a business card with the name Carolyn Wilson of New Hope Drop-In Center. I called her and questioned her about how to run a drop-in center. She gave me some good advice and became my mentor. We had to relocate the drop-in center, but she worked with me. I will always be grateful to her.

Then I started to experience recovery in my life. Hallelujah! We were doing so many things, working on our independence, and just moving forward in a very good way. I was excited and happy about that. In fact, I was hilariously happy. We relocated to a new building in 2000, and it really felt good to be moving forward. Now I was able to dream of better things and create new ideas, and life was coming together pretty well. I found myself able to be a part of this life that I had so desperately wanted to leave. I felt pretty good about the direction we were going.

I met and learned a great deal from Judy and Jeff Robinson about NAMI. I later trained in "In Our Own Voice" and "Peer to Peer."

Along the way I became involved with the Crisis Intervention Team (CIT) and I was playing a vital part in the training of police officers, teaching them about the before and after of people who suffer with mental illnesses, helping to see the

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

Rose Delaney is a remarkable woman. After years of isolation and long-term hospitalization she found her way back to a life filled with possibilities. She is a leader in the fight for quality mental health services for consumers throughout the state. Rose continues to live in Lehigh Acres and work with the Compeer program with NAMI, and she is a proud participant in the Florida Self-Directed Care program. Rose identifies many of the same common threads for recovery that our other storytellers have. She particularly emphasizes the importance of peer support and the value of educating yourself about your illness. She is a wonderful example of the power of helping others.

I knew from childhood that there was something wrong with me; at least I felt that way. I was always so serious. I always had to make sure, even when I was little, that everyone else was okay or happy. Throughout my childhood, I remember hearing my parents say to other people that I was this perfect child. “We take her places and she is so quiet and well behaved” was a common phrase. So I just thought that was it, I was a quiet, well-behaved little girl. Meanwhile, I felt so sad inside and didn’t know how to express this to anyone.

When I started junior high school, I began having horrible panic attacks. I would fear when I got home from school that there wouldn’t be anyone there and I would be all alone. It didn’t matter that this never happened; I was just scared it would. So I started to skip school. I would sneak back in the house and stay there all day. Eventually, the school notified my parents. They brought me to the school counselor. I told them of my fear, and they just said it was the anxiety of starting junior high. Inside, I was just desperate for someone to listen to me. I knew there was something else going on.

High school was horrible. No one realized there was something deeply wrong with me. I think that made it worse for me. I just continued to try to hide it from myself and everyone else. I felt as if I had to live up to the perfect child my parents saw me as. I didn’t want to cause them any problems, so I would keep everything inside. I had suicidal thoughts back then but never acted on them. I was very, very depressed, yet my parents still just thought this was my personality, quiet and well behaved.

Eventually, I got married. I think I went for someone who I thought would take care of me. I didn’t think about his character and how he would treat me, just that he would take care of me. I didn’t find out until the day we went to get our marriage license that he had been married twice before.

At first I was told I couldn’t have children, so it was a surprise when I became pregnant. I had a very rough pregnancy. I was bedridden from my fourth month. This was very stressful for me because I was alone in the house all day. After I had the baby, the stress continued. My daughter was premature and had to stay in the hospital for a month. I just continued to keep everything bottled up inside. The first time I saw a psychiatrist was after the birth of my daughter; I was 22.

My husband came home one day when my daughter was about a year old. I was sitting in the corner on the floor just sobbing. I couldn’t take care of the baby or

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.

By this time, I was suicidal and was placed on 24-hour suicide watch at the jail. I had to wear paper clothes. The guard, who was male, told me to change into them. I told him I wouldn't until he walked away, not realizing they had the mirrors. He walked away, and then I heard them laughing as I was changing. I was mortified! I was detained until they sent me to a local private psychiatric facility a few days later. I stayed in there for about 6 weeks, but the doctor felt I still needed additional inpatient care. My insurance had lapsed out, so they took me back to the community mental health center until a bed opened at G. Pierce Wood State Psychiatric Hospital. This was in 1987.

I was frightened. When I was admitted to G. Pierce Wood, I was coherent enough to realize what was going on. The hospital wasn't in the best of conditions. On arrival, I was taken to the Intake Ward. Most of the people on this ward were pretty psychotic. People were fighting and screaming, and I just sat there wondering how this place was supposed to help me. When I first got there, I was kept pretty heavily sedated, almost zombie like. My dad and my uncle would come up every day to see me. They were very upset when they saw the condition I was in. They set up an appointment for me to see a doctor. At first, the doctors said they had to keep me sedated to get me stabilized. My father didn't understand what they meant by stabilized. He just thought I was drugged and that was it. To him, that wasn't stable. I became okay. I felt protected by two of the older staff members. I think they saw that I wasn't streetwise and didn't know the "in's" and "out's" of this type of facility, so they took me under their wings. Some of the other residents didn't feel so inclined and used to call me Princess. My parents would bring stuff for me, and this bothered them. They would take the stuff that was brought to me and lock it up and not give it to me when I asked for it. So I said something and filed a complaint. The doctor wanted me to tell him who was doing this, but I was frightened because I knew they would retaliate. The doctor kept assuring me that nothing like that would happen. I told him that he wasn't here at night and didn't know. Well, sure enough, something was said to the people who were hurting me. That night, they humiliated me in front of everyone, saying, "The little princess complained so now we can't do this or that and it's all her fault." Of course, some of the other patients there believed this, so it was pretty rough at first.

Eventually, I was transferred to another ward. I tried to make friends with the staff once more because I was afraid that I was going to be mistreated again. The stuff that went on there, I used to say I would write a book about it. Then I thought people would just think I was psychotic if I did tell them some of the going-on. People would think I was mentally ill and fabricating stories. This wasn't the case, though. Things that were happening there were not in my mind. Staff members were having sex with clients. I was at this hospital for more than 3 years. Clients were getting pregnant. There was physical abuse. Verbal abuse was constant. Most of the workers didn't care. I don't mean the nurses or employees who had degrees. Not to sound demeaning, but the other workers weren't educated and were just there for their check and that was it. The night staff in particular would come in and just eat and watch TV. To have gotten better there had to take sheer willpower because you knew for certain that you weren't getting any help from the staff.

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 people. It was in a small office building, so basically all the customers were the same people that came in every day. This was my socialization. I would speak with everyone there, but then I would go home and that was it. I would remain inside my apartment. The doctor would always harp on me about this. He wanted me to get out more for socialization. He would tell me, "I know you can do it, you just have to get out there." I would say okay, but I knew I wasn't ready for that. I was afraid I was going to tell people I was mentally ill, and I was fearful how people would react to this. I didn't even want to tell the rest of my family, like my aunts and uncles. I don't even remember what my parents were telling people about where I was for those 3-plus years.

The only friend I had was my boss. I found the job through job service. I didn't tell her at first, but my case manager kept telling me I needed to tell my employer. I was so fearful that she wouldn't let me stay there, and I loved the job. Finally, one morning I came in and asked her if I could speak with her after work. That whole day, I was so nervous because I thought it would be my last day. Once we finally sat down, I just started crying. She said, "Oh, please don't tell me you want to quit." I told her I wouldn't have to because she was going to let me go. She asked why I would say that, and I proceeded to tell her about my mental illness. She was just looking at me while I was telling her I spent more than 3 years in a state mental hospital and that I currently receive psychiatric care and am taking medication for it. When I was finished, she asked me, "You really thought I would let you go because of that?" I said yes and she said, "Well, Rose, we're kind of a rag-tag group here." It was just me, her, and two other employees. She also stated, "They have stories, too." She said she thought it was just her personality that attracted people in need of help. I remember going to my therapy session after that. I told everyone she didn't say anything. Nothing! Not even a "why didn't you tell me this before I hired you." She acted like it was nothing! I was in such disbelief that people like this really existed.

Anyway, my boss was getting older and was in the process of deciding whether to sell the business. My hours were cut because of this. It just so happened that this woman who came in every now and then for lunch was opening a restaurant. She

offered me a job. I moved at this time as well because I really wasn't driving yet, and I needed to be closer to work. I rented a little cottage off McGregor Avenue. The main house was big and beautiful, and the cottages were where the help used to live. The restaurant was only two blocks away. I worked there until it closed. I think that was approximately 3 years.

I did make a couple of friends. One of them introduced me to another male friend. I was very attracted to him and I thought he felt the same way. Well, to make a long story short, we started seeing each other exclusively. I didn't know, but my family told this man that I had a mental illness. I never told him anything. I felt as if I were 16 again. I was in love! So I didn't have to take my medicine anymore because he was my medicine. I was on a high all the time, not realizing that high didn't necessarily mean good.

My new boyfriend had me sign a Power of Attorney agreement. I put his name on my bank accounts. He then went through all my funds. So, a year and a half later I was penniless, homeless, and suicidal. Once he saw I had no money left, I was no use to him. I came home one day, and there was a locksmith in the driveway. He had all the locks changed and wouldn't let me in the house. When my family found out there was no money, they were very upset with me.

They asked me, "Why were you so stupid to put him on your bank account? How could you be so stupid? What are you doing to do now?" I still had my car, unaware at the time that he hadn't been paying for it. So I went to visit my daughter. I was very depressed. I lay on her couch for 4 days, in the same clothes and everything.

My daughter was getting upset with me and said she couldn't have this. She said no one understood why I was doing this. I told her she was right, that I needed to get my life in order. I told her I was going to go, not telling her what was on my mind. I left her house and got midpoint between her house and Ft. Myers when I stopped at Wal-Mart to get a drink. I remembered it was Hawaiian Fruit Punch. I sat in the parking lot, took a bottle of pills, and drank the fruit punch and proceeded to drive. I still say, to this day, that God was on my shoulder because I managed to make it to the community mental health center. I don't know how; I don't remember anything.

They said when I pulled my car in, I was straddling parking spots and they called 911. I remember when they were putting me in the ambulance I was trying to scream at them. We got to the hospital while they were trying to pump my stomach. I remember flailing my hands and legs and screaming for them to leave me alone. They put me in restraints and pumped my stomach anyway. When I woke up, there was a police officer in the room. Now I was really scared. I said, "I'm being arrested for trying to kill myself!?" He replied, "Oh no honey, we know you need help and I'm just going to take you over to the crisis unit." I lay there and thought to myself, "You're stupid. Everyone was right, you can't even kill yourself! How stupid could you be!?"

So I was taken to the crisis stabilization unit. I think I was there for a couple of weeks. When it came time to be discharged, no one wanted me. I kept telling them

to call my parents, brother, or two sisters. They said they had and none of them wanted me at their houses. I was, of course, shocked. I just couldn't believe this. I didn't have any money; what was I going to do? They told me they were trying to place me somewhere. I said, "Place me somewhere?" I was just shocked that my family would do this. I thought there was no way they would. I said I needed to call my family. So I called my brother, and he said they felt that this the best thing right now. I said, "I have nothing! I have no place to go! This is best?" He said they were sorry but that was how they felt. The mental health center told me that the only place they could find for me was a homeless shelter in Naples.

I ended up at St. Matthews House. When I got there, I saw that it was basically for alcoholics and drug addicts. I told them a mistake had been made and I didn't belong there. They proceeded to tell me there was no mistake, that they were the only ones that would take me. They told me it was either there or on the streets. I called my brother again and told him he didn't understand. I said to him, "I don't think you know where they sent me, this place is for alcoholics and drug addicts. This is where you want me to live?!" He said at least I had a place to live and hung up. At this point, I'm still in shock that my family would do this. It was also well known that people there didn't want me there because I had a mental illness. So I got uppity too and thought I didn't want to be with a bunch of drunks and drug addicts either. I thought I was better than they. I thought it was so far out there. They had me going to AA meetings. I got to my first AA meeting and saw that they all introduced themselves like, "Hi, I'm so-and-so and I'm an alcoholic." I asked what I was supposed to say, "Hi, I'm Rose and I'm mentally ill." I thought that was funny, but the people there didn't because I was making fun of them. I was told not to be disruptive during the meetings. I replied by informing them that I didn't belong there. "What do I have to talk about? I don't drink and I don't do drugs." I said. They replied, "No but you do have a problem, so that is what you need to talk about."

Eventually, we all got to know each other. My nickname became Crazy. It didn't bother me because I knew they were joking. I lived there for a year. I tried working, but I stressed, so I wanted a meaningless job. I got hired at the Hess station to work at the Blimpie's. I was happy with that, making sandwiches. I was there for 1 week when my supervisor asked me if I would consider a management position. I replied that I only wanted to make sandwiches. My supervisor said they had been watching how I worked and liked my initiative. Meanwhile, I'm asking myself why I can't just get a job and stay in the position I want. I went home that night and started having a panic attack. When I was asked why I was having this attack, I said Blimpie's wanted me to be a manager. I said, "I can't do that, I don't want to do that, I can't go back!" I ended up trying another job, and the same thing happened.

It was then that it was suggested that I apply for disability. I had never been on disability before; I had always managed to work. They helped me apply and I was granted disability, which was a surprise. Usually you aren't approved the first time you apply, but I guess they saw my history and that I had tried and I was in my 50s. Perhaps they just thought, "Let's just give her a break or whatever." Once on disability, I was able to find a place of my own. I was living in Bonita at the time,

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 mental health 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 would come and ask questions, I would say yes, and that would be it. Well, little did I know that it would end up becoming one of the biggest turning points in my road to recovery. Judy was that woman. We talked and she told me more about Compeer. I said I'd do it.

Compeers are volunteers from the community who are matched with someone with a mental illness. Usually they'll meet for lunch together or something like that and just start a kind of friendship. It's just like you gain a friend you know is there for you.

So Judy said that she had a match for me. I was going to a cooking class and could meet her there. When Judy picked me up in her car, my Compeer was in the front seat. I couldn't see her face, but I thought her voice sounded familiar. When we got out of the car, the woman and I just stood there looking at one another. As it turned out, I knew her! Her name was Peggy, and we used to go to the same church about 20 years before. Judy didn't know this and asked, since we were looking at each other in such a way. I told her that I couldn't believe Peggy was the one she had picked for my Compeer friend and that we already knew each other. Peggy and I were thrilled. Peggy knew I was sick, although we hadn't spoken in a while. We ended up becoming very close. This was the beginning of my social life. We went to the movies and lunch. I hadn't been to the movies in years. I always used to love going to the movies. There became a waiting list for getting a Compeer friend, so it was decided that Peggy and I would start doing Compeer calls. Four years later, we are still doing the calls. It is as rewarding for me as it is for the person on the phone. When we first started the calls, I was going through a very bad depression in which I thought I would have to be hospitalized again. Then I would hear what the people on the calls would have to say, and it would help me take just one step

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 things, but it really wasn't that way. I felt like I was home. If I said anything, it was okay. If I said nothing, it was okay, I was comfortable. I was seeing other people with mental illness who were doing well. It started to dawn on me that this recovery stuff really works. Each time I spoke, listened, and began learning about my own illness, it just strengthened and empowered me. I think another turning point that made me want to become even more of an advocate was when I attended a certain function. There were some people there who had been in the hospital with me. One was at the level that I call myself at now, and the others weren't. This really bothered me because I knew how they were in the hospital, and I felt they should have been better by now. But I also felt they hadn't been given the opportunities I had, such as the support systems, good mental health care, and an excellent therapist. I thought if they were afforded these opportunities, they would be doing better than they were. This really bothered me and made me want to do something to make it an even playing field for everyone with a mental illness. This became my goal. It almost became a rallying cry.

This was a big part of my recovery, especially when I started doing the NAMI information and referral calls. Calls come in to the NAMI state office. These calls ranged from finding an office near a client to helping someone who couldn't get a doctor's appointment. Sometimes people who call are lonely and just need someone to talk to. It can be a wide range of things. Parents of adult children call looking for advice on how to handle various matters. The biggest thing is that they become very emotional, although their kids are adults now. I just ask them how I can help. I only tell some of them that I have a mental illness. When I do, I briefly tell them where it started and where I am today. Then we both start crying, and the person on the other end of the line is grateful for the hope I give, the idea that their child still has a chance. Never give up hope. If I can give anyone anything, I want it to be hope. I want them to see that they might have a long road ahead, but they will get there.

I never feel as if it is too much for me. People will say that they don't want to put too much on me, but I know what my limits are now and I, not someone else, am making those choices. This was another point that made me realize that the road was getting better. I feel proud of myself now, what I do today, and where I've come from. I don't care what other people say about that. And this is a good thing, especially since it took so long to feel good, proud, and happy. Even if I just help one person, that is enough for me.

If I had to name a couple of other things that most helped my recovery, I would say that one of the most definite things was education. I didn't know all there was to know about my illness. Once I started learning, I would say "Oh, okay, that's what happened and that's what is supposed to happen." That's when I started to realize I wasn't the only one feeling this way. I would also say that support groups made a

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 always so dependant on them. My daughter is very proud. She will just say, "Oh Mom, to see how you were then and now" with such love.

Rose Delaney

Conclusion

State-run psychiatric hospitals across the nation have downsized and freed thousands of people to live in communities of their choice, but the work is not over and new concerns are on the horizon. Most states are currently going through a "transformation" process in an effort to adopt practices and programs that support recovery. At the same time, though, states are experiencing huge shortfalls in their human services budgets. It often seems that the philosophy is going in one direction while the money is going in the other. Most Medicaid services are moving to a managed care system in an effort to control costs. This, by itself, is not the danger; it is that most of these systems are "for-profit" businesses, which is a major change from the long-standing tradition that services for disabled citizens are a function of government and not-for-profit agencies. This rush to privatize mental health care results in increased administrative costs and an overall cut in available services. States must be diligent in overseeing the operations and practices of the corporations with which they contract. If we are ever to achieve the goals of recovery for people with psychiatric disabilities, we must continue to support them in the community and provide services that promote recovery.

Another barrier to supporting people in the community is the rising tide of fear of violence by people with mental illness. Media reports and statements by a variety of advocacy groups who support a return to a residential-based medical model suggest a link between mental illness and violent behavior. But when the statistics are examined closely, it becomes evident that this is not the case for people receiving mental health services. According to the American Psychiatric Association, "people with mental illness who are receiving support from mental health professionals are no more likely to be violent than the general population. Regular therapeutic support from mental health professionals is a major factor in reducing the likelihood of violence" (Canadian Mental Health Association Web site, 2007). These types of supports are compatible with the recovery model and supporting people in the community. When you examine how and where violence occurs among people with mental illness, you see that the incidence of these acts is virtually identical to the incidence among other people who are homeless and

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.

No longer would so many people receive their primary mental health care services through jails and the prison system. Local law enforcement would use diversion practices such as CIT to divert people from the criminal justice system and into services. Mental health courts would offer alternatives to incarceration to people whose illnesses drive their behavior. Instead of shipping people off to state-run institutions to have their legal competency restored so that they can face the consequences of criminal behavior, people would be able to receive competency restoration services in the communities where they live. When people are incarcerated in jails and prisons, the quality of the services they receive would be on par with services in the community, and physical living conditions would be safe, sanitary, and humane.

Consumers would be involved at all levels of the mental health system, and strong consumer organizations would provide a united voice in the design, funding, implementation, and evaluation of all services. They would be employed within the system as mental health professionals and serve on advisory committees and boards of directors for mental health provider agencies and not for profits. Public mental health systems and state agencies would provide financial assistance to strengthen consumer organizations and fund events such as statewide conferences and educational trainings.

A recovery-oriented system would provide support to people seeking social contacts, friends, and activities in the community. Social volunteer and mentor programs such as Compeer are useful for people who have been isolated by their illnesses and resulting poverty. Compeer pairs individuals with disabilities with volunteers in the community as friends and mentors. Traditional services pose a barrier to social integration by surrounding people with an artificial social system composed of paid staff members and other consumers who have to be present because it is part of the treatment. Often, consumers lose their connections to their own family because of the consequences of their illness and the nature of their treatment. A recovery-oriented system would assist people in reuniting with their families and help them to gain important skills for keeping their families together.

Is this imagined system only a dream, or is it a goal? In our world, the world of people living with psychiatric disabilities, it is a goal and an obtainable one. All of these things we have described currently exist individually in mental health systems across this country and around the world. The challenge is to bring them together into a coherent system of care available to each of us. If we are ever able to break the cycle of being a system that is primarily oriented to crisis management and concentrate our efforts on keeping people out of the hospitals, crisis units, and long-term residential programs, then we will have succeeded in obtaining that goal.

People with psychiatric disabilities are just people. We have the same basic needs, wants, and dreams as everyone else. This should be the goal of our system, helping people achieve their goals and find meaning, hope, and joy in their lives. That is the path to true recovery, and that is how people can finally find their way back to the community.

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