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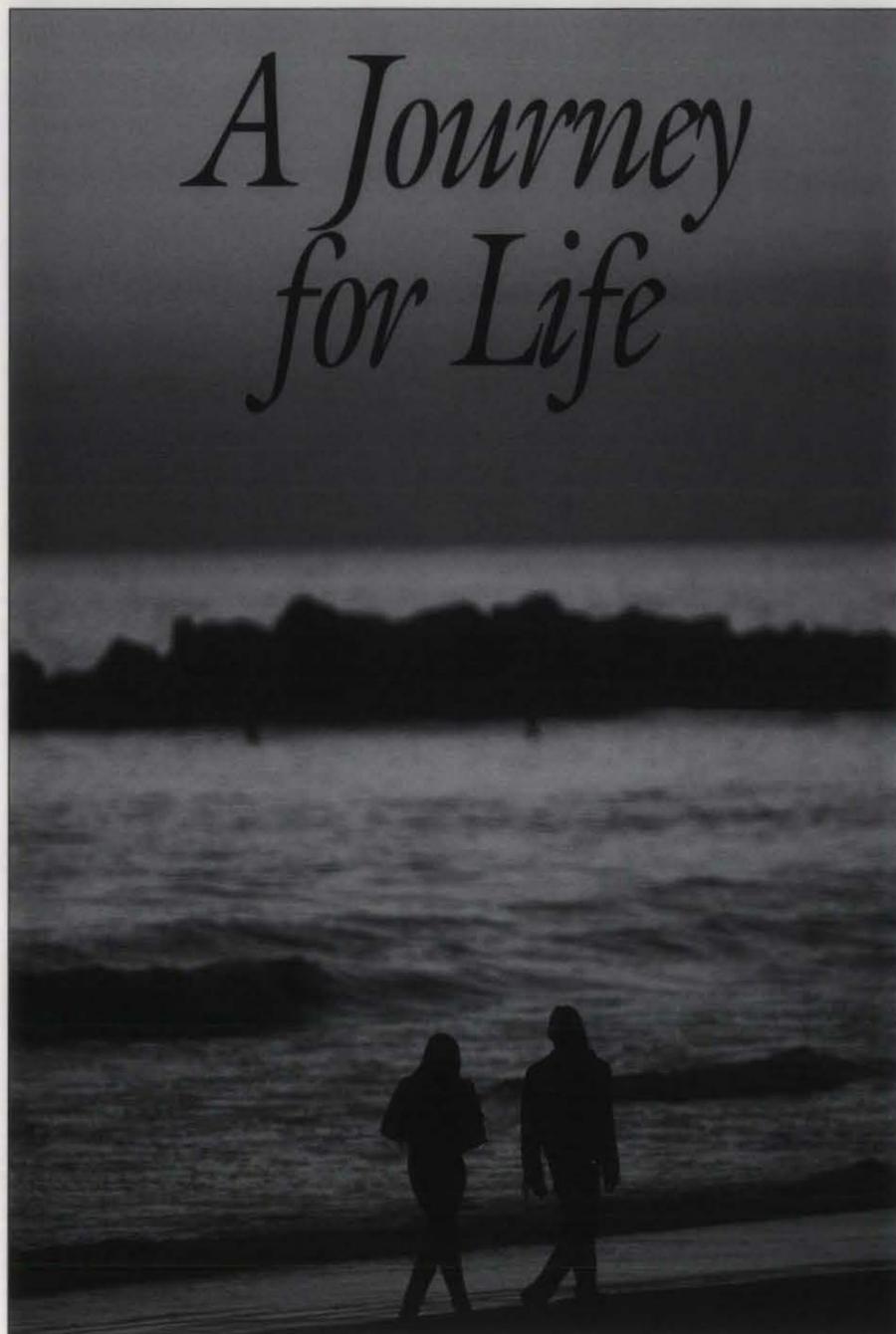
A black and white photograph of a person walking away from the viewer on a path that leads into a dense forest. The path is illuminated, creating a strong contrast with the dark, shadowed woods on either side. The person is a small silhouette in the distance.

A Journey for Life

1999 Rosalynn Carter Georgia Mental Health Forum

RECOVERY

*A Journey
for Life*



1999 Rosalynn Carter Georgia Mental Health Forum
May 14, 1999 • Atlanta, Georgia

A Journey for Life

By ROSALYNN CARTER
*Chair, The Carter Center
Mental Health Task Force*



Several years ago I invited a young man to speak at the Rosalynn Carter Institute of Georgia Southwestern State University in Americus, Georgia. Stuart Perry, who had recovered from deep depression, had never spoken publicly and was very nervous. He said he stayed awake all night preparing for his speech. He made a wonderful presentation about his struggle with mental illness and his recovery. He had all of us in the audience laughing and crying. A representative from the Georgia Mental Health Association was there and asked Stuart to come speak for them. Then he got a job with the state, going from one community to another, telling people about his experiences. Next, he received a grant from the National Institute of Mental Health to tour communities throughout the nation with his message. He is now on a special journey.

On May 1, after a big send-off at home, Stuart began walking from Americus, Georgia, to Chicago, Illinois. He is telling people along the way about mental illnesses and how today they can be diagnosed and treated, and how most people who suffer can lead normal lives — living at home, working, being productive citizens — just as he has been able to do. He is also gathering petitions to present to the American Medical Association at their annual convention, which will be meeting in Chicago when he arrives there. The petitions urge doctors in all disciplines to screen every person who comes into their offices for depression. Through his words, through his advocacy, and through his example, Stuart is expanding the boundaries of understanding of mental illnesses for everyone who crosses his path as he journeys northward.



Stuart Perry

This last week and a half we have been on the road. It has been some kind of week. I never would have dreamt that people would have come out like they have and supported this walk. The crew has been unreal. We are working together, we are learning how to live together, and if you have never learned how to sleep with four or five people in an RV before, it is a good lesson to learn.

We were coming down the road the other day, and these two ladies who had heard about the walk, stopped and turned around in the middle of the road, gave us \$40 and told us, "Thank you for what you are doing." All along the way, we have had people wave and blow their horns. A person drove by the other day and yelled, "I take Zoloft." I yelled, "I take Prozac." It has just been terrific. I do not know what is going to happen, but it is going to be amazing.

The thing that means the most to me is to come out of Miss Rosalynn's home county, the lady that I admire

more than anyone in the world, and to walk to Atlanta. It has been 150 miles and we have walked every inch of the way. Miss Rosalynn has meant so much to so many people and has done so many great things for people with mental illnesses. I told her last weekend I am dedicating this walk to *my* first lady, Mrs. Rosalynn Carter, and to the 30,000 people at Milledgeville who died, because I am an ancestor of the people of Milledgeville.

I have a mental illness, and I am proud that I do, because it has taught me so much about life. It has taught me so much about how to love my family more, how to love my friends, how to love my neighbors. I have so much today to be proud of. One of the biggest things I have in my life is my wife and my little girl. They have always meant a lot to me, but now they mean twice as much.

Miss Rosalynn, to leave the state of Georgia and to walk to Chicago in your honor is the greatest thing I can ever do.

Rosalynn Carter presents Stuart Perry with a Carter Center t-shirt to wear as he walks from Central Georgia to Chicago to raise awareness for mental illness. Perry's tour is funded through a grant from the National Institute of Mental Health.

Introduction

By ROSALYNN CARTER
Chair, The Carter Center
Mental Health Task Force

As we come to the end of the "decade of the brain," we thought it would be appropriate to review what we have learned during the past 10 years and to look ahead to what still needs to be done in the field of mental health.

There is excitement today in the mental health community due to the great strides in neuroscience and what we have learned over the years about quality mental health service delivery programs. These have spurred new awareness and understanding of mental disorders.

Neuroscience has led to increasingly accurate diagnoses of mental illnesses, and the development of new medications with fewer side effects and new treatment methods.

On the following pages, experts at The Carter Center's annual Georgia forum describe the developments in our knowledge of the benefits and limitations of psychosocial rehabilitation services. You will also read about four successful programs from the consumers' perspective and learn about the impact these programs have on individual lives.

Everyone knows that implementing good programs is not easy, and that many barriers must be overcome in establishing and running quality rehabilitation programs. Susan Robinson, head of Georgia's division of the International Association of Psychosocial Rehabilitation Services (IAPRS), details some of

these barriers and some programs that have succeeded in overcoming them.

In Georgia, we have not adopted the Medicaid Rehabilitation Option, and Chris Hendrickson, from the Wisconsin Division of Health and Family Services, describes how his state was able to do so without running into exorbitant costs.

Dennis Westmeier outlines the Lookout Mountain Community Service Board's substance abuse treatment program for adolescents and teenagers, unique for its success in integrating services across state agencies. All of us can benefit from this fine organization's skill in promoting inter-agency cooperation.

Finally, you will read about other projects that have developed outcomes and evaluation instruments for psychosocial rehabilitation programs.

While this year's forum has given us cause to be optimistic about the potential for meeting the mental health treatment needs of everyone in Georgia, we, of course, have not accomplished nearly enough to provide a full spectrum of treatment services for all our citizens. We have made progress, but we still have a long way to go.





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A Revolution in Vision

By WILLIAM ANTHONY, Ph.D.
Director, Center for Psychiatric Rehabilitation, Boston University

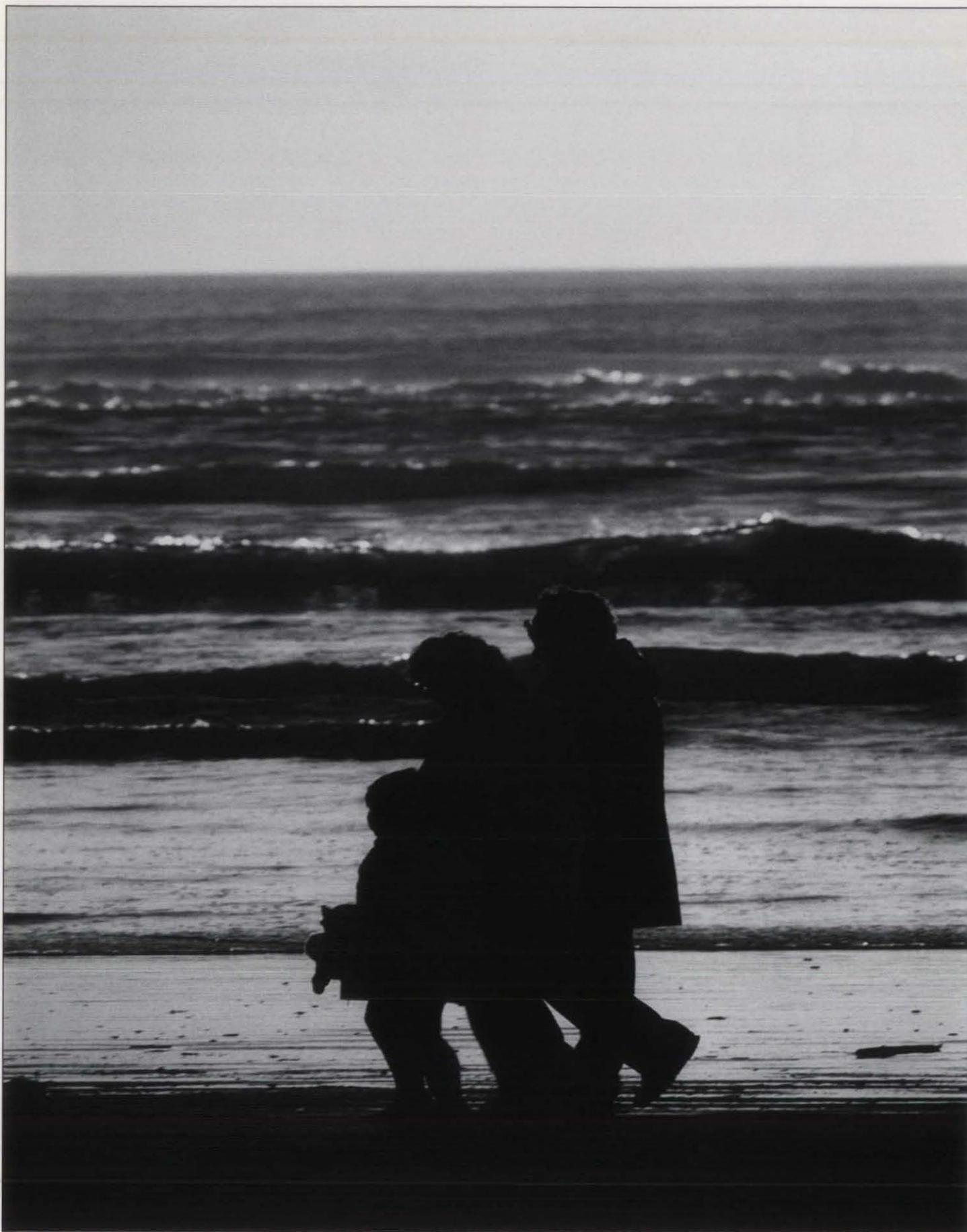


Bill Anthony with Rosalynn Carter

About six years ago, I started an article with these words, “There is a revolution brewing in mental health.” I was not talking about the revolution in brain science; I was not talking about a revolution in medication; I was not talking about the PET scan, CAT scan, nor the MRI. I was talking about a different revolution, the most important revolution, the revolution in vision. This revolution in vision has been brought to us by the consumers of mental health services. I am sometimes a messenger for professionals about that vision. Unfortunately, you know what they do to messengers!

The revolution started when consumers and their family members began to ask a simple question: how much of the chronicity that we see in mental illness is due to the illness, and how much is due to the way that society and the mental health professionals treat people with severe mental illnesses?

It is an intriguing question. Where is the chronicity coming from that has brought about this recovery vision? Consumers have been talking about recovery for some time. But we professionals have not understood its implications or its power. In the past, we were guided by a diagnostic and a statistical manual that said schizophrenia is characterized by acute acerbations with increasing deterioration



Q

Questions & Answers
with Bill Anthony

A

Would it be helpful if the psychiatrist spent some time with the consumers themselves to see it from their point of view? Or maybe some consumers could at least be put into a program, so that maybe they could get involved in helping each other.

Bill Anthony: *I would reinforce both points, the latter being that the consumers — former service recipients — should be in the field and are in the field. They should be trained to be helpful. They may have an advantage right off the bat.*

When we talk to consumers about recovery, one of the first things they say is that what helped them was the person who listened, understood, confirmed, and affirmed. We have to have a place for that to occur in the mental health system. If we have a caseload of 200; if we have 15-minute interactions; or 10-minute interactions with the helper, then we are, by definition, setting up a system which is anti-recovery.

between episodes. If you were diagnosed with schizophrenia, it was downhill and often you were told that.

Now consumers are telling us, and the new manuals are recognizing the fact, that that is not necessarily the case. We have been misleading people. Recovery is a possibility.

Recovery is unique. Everyone feels differently about his or her own recovery. When we talk about recovery, we are talking about the development of new meaning and purpose in one's life as one grows beyond the catastrophe of mental illness. That is the vision we have been talking about.

Some people say vision is not as dramatic as new medication and new neuroscience. I say, on the contrary, that a new vision of what is possible is our great hope.

Think about Down's Syndrome. Twenty to 30 years ago, most people with Down's Syndrome were in institutions. They were not receiving the medical attention they needed. They were not on television. They were not working. They were not doing a lot of things. What has changed? Has the biological marker changed? Have there been tremendous advances in neuroscience that have cured people?

Not at all.

There is only one major change in that field: the vision of what is possible. Look at the dramatic changes that have occurred and marvel at what change vision brings. We have not had a comparable vision of change in mental health, probably since Pinel when, freeing mentally ill people from the dungeons of France, he talked about their need for air and liberty. That was a change in vision.

Today, with the concept of recovery, our vision is again changing. We know people with mental illness can recover, can develop new meaning and purpose, and can get on with their lives.

In fields other than mental health, they act on vision. Think of NASA. In the '60s, President John Kennedy enunciated a vision for the space agency: We put a man on the moon in this decade. It was a vision to which people could relate. I knew what was going to happen. I knew what NASA planned. Today, I do not know NASA's vision: build more rockets, build a space lab? But "a man on the moon in this decade," that was a vision I could understand and get excited about.

"Cure cancer in our lifetime." That is a great vision pulling us into the future.

And that is what a vision does. A vision is not something already occurring, it is a future event, a future condition.

A vision changes the paradigm — changes how we see things. It is like putting new lenses over our eyes and seeing a different world. When humankind thought the earth was flat — it still looks flat to me, but apparently it is round — we had a flat earth vision. But when we discovered the earth was round, all the questions changed. So did some of the answers. That is what happens with recovery.

Iremember a fourth-grade picture of a sailing boat on a flat earth; at the edge were monsters. The boat looked like it would sail right into the monsters' mouths. What were the questions we asked then? How long do you have to sail before you fall off the end of the earth?

What are those monsters like? Will you be eaten up?

The questions changed the minute we learned the earth was round and monsters did not live just beyond our horizons. In mental health, we are still asking a lot of "earth is flat" questions. But we should be asking "earth is round" questions. Earth-is-flat questioning include:

- PARENTS OF MENTALLY ILL CHILD: "What do we do with our unmotivated sons and daughters?"
- MENTAL HEALTH PROFESSIONALS: "What do we do with our unmotivated clients?"

The question they — and we — should be asking, however, is: "What do we do with our unappealing and ineffective programs?"

I always was amazed when program directors talked to me about unmotivated clients. They thought they were diagnosing the clients but they were diagnosing their programs. We need to think about programs that do not demean and infantilize the people we are trying to help. People leaving a program is an indication of the program's failure. We need to rethink our values and come up with terms other than "compliance." We need to come up with language that does not talk about "caregiver burden." Consumer friends of mine say, "I do not want to be called a burden. People might have to exercise more or different responsibilities because of me, but do not call me a burden." If you go back and think of our language and our values, there is so much that is anti-recovery, it is hard to believe that people are recovering. But they are, sometimes in spite of our unappealing programs.

Unappealing programs combined with uninspiring people who run them

are a major barrier to recovery. Maybe a person is healthy because he or she does not want to go to a poor program just to sit around and watch television, discuss events, and smoke cigarettes. Maybe that is a sign of recovery, rather than lack of motivation.

Another "flat-earth" question: What jobs are the least stressful for people with psychiatric disabilities?

The new question is, what jobs do people with psychiatric disabilities want?

When I first got into this field, some textbooks said people with severe mental illness should be in certain jobs, depending on their diagnosis: People with mania should be sales people; people with depression should be librarians. You know the stereotypes.

We did not look at goals, interests, and values. We looked at pathology. And we said, "Their life is determined by pathology, what should be their vocation?" The new question is, What do people want to do?

We are doing a stigma buster study right now; we are getting tremendous information to help in planning new programs. The people filling out surveys have white-collar jobs with budgetary or supervisory responsibilities, even though they have been or are severely mentally ill. We do not hear about people like that. We think those jobs would be too stressful. As if working at McDonalds is not stressful.

Of the 400-plus who have responded so far:

- 42 percent have a masters degree or higher;
- 45 percent earn more than \$40,000 a year;
- 31 percent are married.

Q

Questions & Answers
with Bill Anthony

A

You talk about only wanting employees who are caring. Regardless of diplomas, how good is our system at teaching people how to show their caring in ways that will be helpful for different consumers with different particular needs? What parts of a training component do you think are important to teach people to show and use their natural caring in this work?

Bill Anthony: *We cannot teach all people to care. However, we can certainly remind people, we can certainly reinforce it, and we can teach people how to listen and how to try to understand. We can teach people to stop asking stupid questions, rather than listening or understanding. So there are elements of caring that can be taught. We can look at the program structure and take away some "uncaring pieces" — conditions or settings that create a non-caring environment.*

Q

Questions & Answers
with Bill Anthony

A

Where do the delusions come from in schizophrenia.

Bill Anthony: *I would not hazard to answer your question from here. Some people do understand where their delusions come from. Others do not. But even if one cannot understand the source of delusions, even if they remain a mystery, he or she can recover. People can have symptoms, yet develop new meaning and purpose in life, even though they have not been able to figure out why they got this way or exactly what cause their symptoms to be this way. People do recover in spite of that. That is the good news.*

Their psychiatric characteristics:

- 84 percent are on medication
- 42 percent were on SSI or SSDI

at some time in their life.

Their typical diagnoses are as expected: bipolar depression, schizophrenia, and schizo-affective.

- 84 percent have been hospitalized, 41 percent within the past three years, 57 percent three or more times.

They are people who have the diagnosis of severe mental illness, yet they are out doing a great job. And they do not mention "job tasks" as the most stressful thing in their lives.

What is most stressful?

Fitting in, feeling different, supervisors who do not understand psychiatric disability.

How do they cope with their disabilities on the job? Take a break, exercise, meditate, talk to friends or a counselor.

Another "earth is flat" question is, "Are integrated settings always the best for rehabilitation?"

The question should be, "What settings increase a person's success and satisfaction?"

At times, you can have a "segregated setting" within an integrated environment. In the integrated setting of the Boston University campus, a computer-training program for people with psychiatric disabilities has been extremely successful. It is a yearlong program with a two-month internship concluding with a job development and job support application. It is a setting that is designed to increase people's success and satisfaction. The diagnostic pattern for the 60 people who have completed the program indicates severe mental illness. The outcomes

of the first 60 graduates: 73 percent got jobs, 60 percent in jobs that require computer skills.

The drop-out rate for this program is five percent. The attendance rate is 90 percent.

Wonderful things can happen if we start to develop the programs that people need.

A fourth "earth-is-flat" question is, "What credentials do we need to practice in this field?"

The "earth is round" question is, "What characteristics make a person helpful?"

I get concerned when people talking about their program say they have 1.3 social workers, .2 psychologists, 4 LSW, 2 LPN's, etc. That does not say anything about the program. That does not tell people whether the program is helpful. We have been trained and acculturated to look just at credentials, rather than what is helpful. Can the person teach? Can he/she inspire? Negotiate? Connect? Can he or she engage? Those are the things that are important. That is what most people who are entering the programs want to know.

A woman in a graduate class of mine, who happened to be a consumer, said to me, "There are only two things that I want and I have been in this system a long time. I want somebody who is competent and I want somebody who is caring. That is what I look for, competent and caring." To her, it was that simple. In the past, I have asked people whether they could tell who was caring for them when they were severely symptomatic. They replied, "Without a doubt, I could tell who was caring and

who was not. I could still make that de-termination."

I gave a talk in Buffalo, New York, and a former principal of mine, now in her eighties, was in the audience. She came up afterwards and introduced herself to me. She said, "There are two types of people in this world. That is all you need to know. There are those who care and there are those who do not. Hire the former and fire the later."

We tell our staff that there are things we do not understand about mental illness. We do not always know quite what to do. But we can care. There is no excuse for not caring. Caring is independent of credentials.

Another "earth is flat" question is, "How do we get the person to change so that they can achieve their goals?"

The "round-earth" question, the recovery question, is: "How can we get the environment and the person to change, so the person can achieve his or her goals."

The focus is no longer just on the person, the focus is also on the environment and how the environment facilitates or hampers recovery. For so many people, the environment is getting in their way. The way the mental health field, professionals, and society treat people with mental illnesses needs to focus on changing the environment as well as the people.

We can walk in an institution or a mental health center and assess it to death. However, it is obvious when there is no caring going on. It is easy to tell when there has been little effort made to maximize the environment for people. For example, you walk in and there is a

big glass wall which the receptionist sits behind. You have say, "I am Mr. So and So," trying to get attention. What kind of first impression does this make? Or you are walking down the hall and you see "Staff Restroom" and then the other restrooms. Can the staff not use the same restroom as everyone else?

Environmental things that are demeaning, infantilizing, and point toward the mentally ill person's "differentness" do not deliver messages that help people recover. Ask consumers about the kind of environment you provide for them. They will tell you the things that really turn them off.

An additional "earth is flat" question is, "Is not recovery just for high functioning persons?" The "earth is round" approach says that recovery is for everyone — high functioning and low functioning. Those terms are not useful anymore.

Directors of programs want consumers who are highly skilled, not symptomatic, and highly motivated. That is who they want in their programs. If we had that person, we would not need their program! People are not symptomatic 24 hours a day, 365 days a year, because we have medications, we have community support programs, we have rehab, and we have family support. This high functioning/low functioning distinction does not cut it anymore.

It is a poverty-stricken environment rather than the functioning of the person that is the biggest barrier to recovery. A psychologically and physically poverty-stricken environment does not have the resources to heal physically and affirm psychologically. The environment is a barrier to recovery. That is more important than diagnostically figuring out if a

Q

Questions & Answers
with Bill Anthony

A

What do you recommend for people who experience mental illness but still function well in society, in the de-stigmatization of mental illness. In general, we are not out of the closet, we are not public, but we keep society running. How can we help with de-stigmatization?

Rosalynn Carter: *The more people speak casually about being mentally ill, the more it helps anybody and everybody who has a mental illness. When you say, "I have depression," just like you would say, "I have a cold," that is when we are going to be able to help overcome the stigma.*

Bill Anthony: *You really need to call people on it when they make stigmatizing remarks. It is time to say, "Wait a minute. Are you making fun of people with all sorts of disabilities or just the mentally ill? What's going on?"*

Q

Questions & Answers
with Bill Anthony

A

What can we do when we hear our treatment people stigmatizing the very people they are trying to help.

Bill Anthony: *That is a difficult question, because one of my biggest disappointments, I think, is the fact that we do not have a new generation of treatment professionals who understand rehabilitation and who understand this type of thinking being trained. For the most part, many folks are still being acculturated into that old system. My hope is that as consumers and family members get more involved, radical changes will be made in the attitudes and enlightenment of treatment professionals.*

Rosalynn Carter: *There is one other thing that I would like for you to do. If we could get coverage for mental illnesses on par with coverage for physical illnesses, so that there was insurance that covered everything, it would destigmatize mental illness. It would be all right to have the illness. You can write your Congressperson and your senator and tell them to vote for legislation to assure insurance parity for mental illnesses.*

person is high or low functioning.

The final "earth is flat" question is: "What happens if consumers do not achieve their goals?" When we were first developing psychiatric rehabilitation, we said we want people to set goals and get involved in their goal setting, to make choices and have options. Some people asked, "What happens if they do not reach their goals?"

The "earth is round" question is: "What happens if they do not have a goal?" Benjamin Mays said, "It must be borne in mind that the tragedy of life does not lie in not reaching your goal; the tragedy lies in having no goal to reach. It is not a calamity to die with dreams unfulfilled, but it is a calamity not to dream. It is not a disgrace not to reach for the stars, but it is a disgrace to have no stars to reach for."

When we talk about civil commitment now, we talk about people "dying with their rights on." People are also dying with their dreams turned off. We need to let people dream and talk about their options and their goals. Nobody reaches all their goals, but think how terrible it would be if you had no goal. That is what we are doing to a lot of people. We worry about whether people are going to crumble if they do not reach their goals. There are so many people who are okay without reaching all of their goals.

In tough times, when there is little money, and there usually is not enough money for mental health, you need to dig into the recovery vision. It is easy to have a vision when things are going well. Consider George Washington at Valley Forge. His troops had little food, little money, little clothing, and no shoes. That was not the time for Washington to say, "You

know, life wasn't too bad at Mount Vernon. I think I will go back." In contrast, that was the time that he had to dig into the vision of "life and liberty for all." That is when the vision is most important.

I was recently reading a new biography of Robert Frost. Frost has a line in "*The Death Of A Hired Hand*," where he is talking about Silas and he says, "*Silas has nothing to look forward to with hope, Nothing to look backward on with pride.*"

I would like to re-write those lines to say what the recovery vision speaks to us about. We want to try to "instill pride in things done but since forgotten, and instill hope in things undone but still possible." That is the challenge of the recovery vision.

We have a tremendous opportunity in this state. In speaking about opportunity, Thomas Edison once said, "The reason people do not take advantage of opportunity when it comes knocking on their door is it is dressed in overalls and disguised as hard work."

You have a lot of hard work ahead to make that recovery vision and rehabilitation work in this state.



Programs That Work

Our consumers have taught us a great deal. When we sit together to talk about goals and their life views, we do not talk about symptoms. We do not talk about weaknesses. We talk about strengths.

JEWELL POWELL
Director, Community Rehabilitation Programs

Gwinnett/Rockdale/Newton Community Service Board

For about 20 years, Gwinnett/Rockdale/Newton Community Service Board has been providing psychosocial rehabilitation services in a variety of sites and have been part of the evolution of change that has gone on in Georgia. Our greatest change has been the partnership now forged between consumers and staff in identifying what their choice of life is, and seeing these people in terms of their personhood rather than in terms of their symptoms.

There is a common ground now as we support one another to make the program successful. Our consumers have taught us a great deal. When we sit together to talk about goals and their life views, we do not talk about symptoms. We do not talk about weaknesses. We talk about strengths. That has been a true evolution in our practice. We also have at the table their family members, and I cannot say enough about what a difference it has made having the Georgia association of family members — the National Alliance for the Mentally Ill, and the Consumer Network — to support programming in Georgia. Without them going to the legislature for money, we would not be where we are today in providing services.

We must acknowledge the community of providers and the community of caring that we have been able to build. We are a community of people who care about people with mental illnesses.

Through our focus on work, and our focus on helping people get the treatment they need to deal with their symptoms so that they will be able to work, we have accomplished our goal. We have exceeded our Twenty to Work by 2000. We go into the millenium hoping to have a much better percentage of people working. Currently our programs serve five different sites in the Gwinnett/Rockdale/Newton service area. We have served about 300 people. Over 100 of them have been working at least part of this year; most have been able to work for over nine months. We are really proud of that.

KATHI GOODWYN
Consumer

Gwinnett/Rockdale/Newton Community Service Board

I have suffered from major depression and minor depression, on and off, most of my life. Like many other people, rather than get help from a doctor, I self-medicated for many years. Then I discovered that I could not do that any more, so I went into drug and alcohol recovery about six years ago. I was doing very well with that.

Last year, there were many changes going on in my life and I went into another major depression. This one was totally different than any of the others. I had come to the conclusion that I just did not want to live anymore. I was just too tired. That brought me to GRN. I came voluntarily, but I did not want to be there. I needed to be convinced that there still was hope, a reason, a purpose.



Q

Questions & Answers
with Panelists

A

What problems did you encounter in setting up the Roy Thagard Center?

Richard Van Ingram: *The major problem was determining its focus. It was difficult finding out exactly what consumers need.*

Through the efforts of people at GRN who really care, I was able to find that.

I like rehabilitation programs when they include many facets, instead of just going to the hospital, getting some medicine, and being escorted to the door. I got to stay there. I had no home to live in because I could not keep a job. They took me in at Crisis Hospital. It is one building with only about 20 people. Being in a small environment enabled me to gain trust in the people who were trying to help me. I had peer support from others who were like me.

I am grateful for that step in my life. It was just like taking baby steps, coming out of this fog. Everybody in the GRN system was very helpful. There were people that I did run into that were not quite as nice as others, but you could avoid them.

Then, we went to a partial hospitalization program. It is a pretty heavy-duty day treatment, 9 a.m. to 3 p.m. There are just a few breaks. They make you talk about yourself the whole time, which is not comfortable. But it is so helpful, now that I look back, help coming from all these different directions. I suppose you could say I graduated. I decided to live and that enabled me to get help from GRN's community housing.

I never knew such a thing existed. When I was hospitalized about 25 years ago, I stayed about two weeks, got medicated, and they gave me a bus ticket. There I was, out on the street with this medication, but no place to go. In GRN, it was not like that. They helped me find a place to live. They supported me financially until I was able to work. That is what is so rewarding about it. It was "until I was able." It was not, "We are going to do this for a week, then you have to get a job and do this and this and this."

I started out as a receptionist answering the phones for Jewell; it was such fun. I worked for NASA for 27 years, in a very fast-paced environment. To be a receptionist for two hours a day was the nicest job I ever had. I thought, "This is great. I am going to stay right here." But of course, after two or three months, I needed more. I was getting better, so

now I work for the employment program of GRN. When it comes to helping consumers find jobs, we have coaches and training instructors and all kinds of help. If the consumer wants a job, he or she certainly can.

I worked as an office assistant; they treated me as though they would not be able to make it a day without me. That feels so good. I do all the computer work and my immediate supervisor thinks that I perform magic — he does not know much about computers. The day treatment program is staff-run, but consumers are asked what they would like to have in the program. It is a team decision. It is rewarding to be a part of your treatment.

CISSY BEST
Consumer

*Roy Thagard PEER Center,
Cleveland, Georgia*

Even though our program is new, we have already had great success. I am a success story. This time last year, I was severely depressed and considering suicide. Through PEER support, here I am.

I would like to tell you a little bit about this special man, Dr. Roy Thagard. I did not know him as a pediatrician and addiction medicine specialist. The Dr. Roy that I became briefly acquainted with was the cutest little man with a questionable fashion flair. Every week he brought his old Labrador "Boo Boo" into the vet clinic where I worked. Since I have always identified better with animals than with humans, that put him right up there in my book. I did not know about all the contributions that he had made to addiction medicine and mental health until after he passed away. I am tickled to death to be working in a facility that has his name.

The word PEER in the Roy Thagard PEER Center is an acronym standing for Peer-Support, Education, Employment, and Recovery. I'm changing the word order to reflect importance.

Employment — Jobs are a means of integrating consumers into the com-

munity. The job coach is the person to aid in this process. At the PEER Center, the job coaches' task is to mediate between the consumer and the community of which he is attempting to become a part.

Education — Through preparing a consumer for employment, it may become apparent that extra skills are needed. We obtain GED support for those without diplomas, and literacy training for those with deficits in reading. There is also a training program in English as a second language.

The Center supports a new computer lab with eight workstations, a multitask printer, and an internet connection at one station. Our lab instructor, James Ivy, teaches three classes weekly at 12-week intervals. In these courses, students from various day treatments learn the basics of computer literacy including Windows 95, Microsoft Word, and Powerpoint. The students are also introduced to the Internet, Netscape Explorer, and strategies for research on the Net. All of these educational tools broaden the horizons for consumers entering the job market.

Peer Support — The Center will soon offer support groups for consumers, their families, and the community. Presently, we host the Double Trouble in Recovery 12-step program for consumers who have both a mental-health and substance-abuse diagnosis. Our work support group is designed for consumers who are working or are interested in work. Consumers examine their goals and their plans to achieve them, share experiences, and offer advice. A Co-dependence Anonymous Group is being organized. It is for anyone who wishes to work a 12-step program aimed at developing healthy relationships. We are developing a family-support group for the families of working consumers, where they can discuss the problems and benefits of the consumer's transition to the work force.

Recovery — Everything we do is in the name of recovery. Recovery is not a destination, so much as it is life lived at a certain level. It strives to make a life that is as deliberate and conscious as can be.

Therefore, our aim is to provide consumers with the tools they need to pursue their recovery and to participate in the life of their communities by means of work, education, and support.

RICHARD VAN INGRAM

Consumer

*Roy Thagard PEER Center,
Cleveland, Georgia*

I could summarize the mission of the Roy Thagard PEER Center with these words: *We help consumers find and keep jobs.*

Why is it important that we help consumers with work in the first place? That is essentially the same thing as asking why the Roy Thagard PEER Center exists at all. For many, work is something to dread. Many people work in the present, only so that they can avoid more work later on. It is as if work were something foreign to being human. Under such thinking, work is reduced to mere labor, yet another difficulty to be encountered in life, or a form of punishment to be avoided at all costs.

In the face of such a pessimistic view, why are we attempting to make it possible for people with various disabilities to enter the work force? The answer lies in the belief of the Center that not all work is drudgery. More important, it lies in our conviction that work is therapeutic, and that it is therapeutic precisely because part of what it is to be a human being is to act creatively and contribute to one's community.

A great deal of emphasis has been placed in recent years on the necessity of spirituality in recovery. I have no dispute with the value of spiritual practices and their necessity in a good life. But there is another element in us, besides the spirit, that longs for recognition and satisfaction. That part is the psyche or the soul. While the spiritual is the vertical element which tends to reach for the abstract and which reinforces the ego, the psyche is the horizontal plane of our existence, longing for the particular, requiring ritual

Q

Questions & Answers
with Panelists

A

Can you tell a little more about the role of the job coach at the Thagard PEER Center?

Cissy Best: *The job coach begins by going to local businesses and preparing management to hire people who have a diagnosis of one sort or another. Often this requires the coach to overcome stereotypes on the part of well-meaning, but misinformed, business owners. The job coach also works to boost the confidence of the consumer and allay unreasonable fears, evaluate abilities, and determine likes and dislikes.*

The job coach evaluates the preparation the consumer needs before entering the work force, and helps the consumer obtain it.

Q

Questions & Answers
with Panelists

A

I go to a mental health co-op; they offer me a case worker or therapist, and a doctor. I do not get the therapy I need. The therapist said she was not going to fight for me. I had to pay \$40 a session to see her. When I spoke to the Social Security office, they told me there was nothing they could do to help me. How do I get the medication and therapist I need?

Dr. Lewine: *Virtually all of the pharmaceutical companies have patient-assistance programs to help with finances. It takes a little effort to get the right names and telephone numbers, but you can track them down.*

Finding the right therapist could be a long process. Keep trying until you find someone you can work with. We always counsel people, whether a family member or a client, to shop for their doctor. You are the consumer. Ask appropriate questions. The other side of whether therapy works or not is whether you like the doctor. You have to keep at it. That may not be easy.

Doctors are in increasingly short supply, and therapists are absolutely swamped. It is a significant problem.

I am sorry to say that you are one of the many results of what we are facing in today's health care system.

and pattern, and desiring to discover or make these from the stuff of experience.

The psyche desires community, union, and stronger bonds between self and others. If we imagine the spirit as that part of us which reaches upward and away from the world we all inhabit, and if we imagine the body as pointing downwards to the here and now, we can see that the soul's function is to mediate between the two. The soul integrates body and spirit, worldly and otherworldly ambitions, present and future plans.

What does this have to do with work? Everything. True soulful work, performed from intrinsic necessity, is one of the psyche's primary means toward wholeness within the person. In spiritual practices, emphasis is laid upon withdrawal from the world, or at least upon a temporary suspension of attention to worldly needs. In soulful activity, the world is given full attention, not lavishly, but as a means to self-fulfillment. Thus, it is possible that the routine of making a bed, filling out forms, or frying burgers could become as much a life-affirming ritual as painting a picture or composing music. When a person is pathological, all his energy and attention is focused on himself. Work should spread some of that energy and attention outwards. Therefore, getting a job can be therapy. But our role in the therapeutic process is not one of therapist/client. The name of our center is the PEER Center. In the usual arrangement, consumers receive help from staff members.

The Roy Thagard PEER Center represents a shift in emphasis and an augmentation of the caregiver/client relationship. Just as I have shown that work is therapeutic, I would like to recognize that there is something intrinsically healing in having contact with one's peers in a therapeutic setting. All permanent staff members at the Center are consumers of one sort or another. Consumers are, therefore, speaking with people who know first-hand what it is like being mentally ill. They are people who understand how frightening it is to go out into the community, to attempt to find a job, and to make oneself understood in an unfamiliar setting.

The distinction between staff and consumer is purposely blurred, without becoming chaotic, in the hope that therapy can become more of a partnership. It is also our desire that the consumer will take some hope in seeing what another consumer can accomplish.

Let us discuss work in more common terms. Everyone has heard that one of the main reasons that consumers need to work is because a paycheck represents freedom. With money, I can pay my bills, which frees me from servitude. It allows me the self-determination to plan a future. More deeply, the work I do stabilizes and grounds me. There have been many mornings when I did not think that I could get out of bed, but my responsibilities gave me a reason to go. The rhythms and patterns of work help me on days when my ability to think creatively or even clearly is impaired. Work organizes my life.

The self-worth and dignity that work can bring come from a sense of adding to the community rather than simply being borne along by it. The alienation that often accompanies mental illness can be broken down when one plays a role in a goal-oriented work place. Standing alone when one is depended upon and valued by others is difficult.

COLEEN COLLINS

Consumer

*Community Friendship, Inc.
Atlanta, Georgia*

When I was 24 years old, in the first days of July 1986, I started to feel fearful. That fear turned into panic. My heart started racing. I started feeling like I had to run and scream. My skin felt like it was on fire. Needles were just burning into my skin. I had a strong urge to kill my mother. I had pictures in my head showing me how to do it.

This scared me very much, so I admitted myself into the Veterans Administration Hospital in Decatur. I stayed in the hospital for over a year. Toward the end of my stay, my social worker asked if

I wanted to be in a day program. He referred me to Community Friendship's program. I was accepted into their clerical unit, which was good because it structured my day. It kept me busy and gave me something to do. It helped me to brush-up on my typing as well. In 1991, I became a volunteer at Community Friendship in the clinical records department.

Also at the end of my time at the VA, I was placed with a family. I lived with this family for almost two years. Then I moved into Community Friendship's Group Home. I was very happy because it was something that I really needed.

I am afraid to be by myself at night, because that is when all my demons come to bear. It was good that someone was there 24 hours a day that I could go to if I needed help.

I had very good support from Community Friendship. I also had a Compeer friend that I would go out with. I think that this support from Compeer and Community Friendship helped me to stay out of the hospital. June of this year will be two years since I have been in the hospital.

Community Friendship has encouraged me in everything I have done. They encouraged me in my poetry, and they encouraged me to try to get it published. There is one person in particular in Community Friendship that has been my rock. I have been able to speak to her about anything and everything. I think that has helped me to stay out of the hospital also. I have two poems that I want to share.

The first poem I wrote when I was in the grips of my illness.

*Momma, Momma talk to me
Tell me what they want of me
Screaming, yelling in my head
Made me wish that I was dead
Made me want to kill and maim
No one wins this deadly game*

*Help me put my mind at ease
Tell me what they want, oh please
Killing is not the way I see
Suicide is there for me*

This is the other poem that I wrote more recently.

*Can you see into my mind?
Into all my secret places
Just what do you hope to find?
Feast your eyes on all my faces
The horrors are all there
The sights, the sounds, the grief
The things to me, they scare, they give me
no relief*

*Paranoia has set in
I am such a joy to be around
It seems I cannot win
All around me fears abound
But today, I find the sun
I have made it through the night
This battle I have won
And in this joy I can delight*

JEANETTE DEPOY
*Director, Staff Development
and Training*

*Community Friendship, Inc.
Atlanta, Georgia*

The very first time I ever came to Community Friendship (CFI) was in October 1985. Jean Toole was interviewing me for a job as a project director; I can still remember the way CFI felt from the first moment I put a foot inside the door. The people there were upbeat, friendly, and positive. They were laughing. There was an environment of hope and recovery that I felt immediately when I walked inside.

How is that atmosphere created? What is the key that unlocks that kind of hope?

There are several keys. One key comes from creating your programs and services based on what consumers tell us they want. For example, when Community Friendship began in the late 1950s, it was basically a social gathering place. But consumers wanted more. They wanted something more constructive to do than sit around playing cards all day. This led us to create our day program.

Q

Questions & Answers
with Panelists

A

Shouldn't consumers be taking more initiative in talking about and learning about their medications?

Jeanette DePoy: *Taking medication is really a core area in rehabilitation and recovery. We need to change our attitude to encourage people to learn how to manage their own illness. That involves more than knowing what your medications are. It is understanding what place they have in your life, your attitudes about them, what you are going to have to put up with to take them, what the options are. It is a much more complex arena, but it seems to be the only way to go.*

Q

Questions & Answers
with Panelists

A

A couple of years ago, I had an experience that was quite frightening. I felt a presence in my home, similar to what Coleen said about demons. It was hard pulling myself out of it. I found that my faith, prayer, and certain foods and vitamins helped. Does nutrition help recovery, or even prevent mental illness?

Jeanette DePoy: *I do not know much about the research on that, but I do know that anything that we can do, consumers and staff, to take care of our bodies, whether it is good nutrition, exercise, vitamins — that sort of thing — is beneficial to our minds as well.*

Then people began to say that they did not want to go to a school where nobody ever graduated. So our work-opportunities program was created.

Each time CFI created a new program, it was in response to a need presented by our consumers. Now consumers at CFI are offered a menu of services from which to choose. We ask them for input constantly. The consumers are no longer shy about telling us what they think because they know that CFI will try to give them what they ask for. The consumers have seen us put in new rules, they have seen us add new equipment and new services, all based on their ideas.

A second key is that we all need goals. Research shows people live longer if they have goals. The first day of my interview at CFI, I met a man I will call Joe. Joe was talking to our Executive Director about wanting to go to work, but being afraid because he did not want to lose his SSI check. For a time after I began working there, Joe would tell other consumers, "Do not go to work. They'll cut your check right off." We had to tell Joe to let other people make their own decisions. A few years later, after seeing some of his friends go to work and enjoy a paycheck, Joe decided to take the risk. He got a part-time job. He was so proud. I remember talking to him later with absolute amazement, because he was so excited about paying income taxes for the first time. Imagine somebody who actually looked forward to April 15. When Joe joined our retirement plan, he said, "I have to think about my future."

That is exactly what we try to do at Community Friendship: help people think about their future.

There are two important rules at CFI. The first one is, "Members come first." The second is, "When in doubt, do the friendliest thing."

Another key to our service is our staff. Staff are advocates. They go places with you when you are afraid. They teach you skills. They give you knowledge that you need. More important, they listen at a deep level, with their heart, to what the person thinks, to what the person feels, to what the person dreams.

They act as a kind of cheerleader,

telling you that you can do it until you actually believe that you can. They have faith in the consumers, and they stay around even after you succeed, just in case. The consumer literature has taught us that recovery is usually not a linear path. There are peaks and valleys along the way.

Dr. Patricia Deegan, a consumer professional, has taught us that the best programs are fail-proof. If you try and you fail, you can always come back. Talk about the experience, talk about what you have learned, and try again. The staff is still there to celebrate any new successes in your future.

Education is another key at Community Friendship. Skill classes are offered weekly to anybody who is interested. Skills that our consumers have wanted to learn include expressing feelings, especially anger, budgeting and saving money, recognizing symptoms, and how to ask questions of professionals, which can be one of the hardest things to do.

Classes around the illness are crucial. People are interested in knowing what the latest theories are about the causes of mental illnesses. How should they talk to young family members about their symptoms? How do they recognize their own early-warning signs? In those classes, I ask the class participants which is worse: dealing with the illness and its symptoms, or dealing with the stigma of a psychiatric disability. They always tell me dealing with the stigma is worse.

Many people thought of themselves as *a* schizophrenic, as if that is what they did for a living. We try to help people say, "I am not this illness, this disease, this label. I am a person with a disability." We want this to be a no-fault illness. We want the person to be able to move on from the illness to recovery, so that the illness is no longer the center of their life. Their life is the center of their life.

Our consumers tell us that family is the most important thing in their lives. Family members must be educated to understand how their loved one feels about the illness, and to stop blaming themselves.

Communication and problem-

solving skills are helpful not only to families and consumers, but to staff. Family members tell us that these classes have given them hope for their own and their loved one's futures. It has taught them to be angry at the illness instead of being angry with the person.

Fun and enrichment are important to us — taking a Tai Chi class, going bowling, learning to take photographs, playing softball, learning to sculpt or dance. Each of these activities is another chance for somebody to have a success. People need this time for relaxation and fun. CFI strives to offer it on a daily basis.

The attitude of the staff about mental illness and consumers must be unconditionally positive. Staff must have high energy and enthusiasm that rubs off on everybody. If the staff do not believe that people can recover, go back to work, have a family, and have a life, the consumers will not.

Staff training includes an experiential in-service that is called, "Hearing Voices That Are Distressing." You do this while you go through a mental status examination with a psychiatrist, while you participate in the day program, while you go out into the community and do a task, and while you have psychological testing. The staff at Community Friendship told me that this is the best training they have ever had, in or out of school. They say, "You think you understand what it is like, but you do not have a clue until you have a taste of this."

Our staff training also includes psychiatric rehabilitation, using the approach and technology taught by Dr. Anthony and others at the Center of Psychiatric Rehabilitation in Boston. This helps our staff assist, inspire, and coach consumers in reaching their goals. We also include some exercises to help staff appreciate what it is like when people try to take away the most valuable things in your lives. What is it like to have your values taken away from you? Staff must also love their work, and enjoy doing it.

The last key to recovery is spirituality. This is maybe the most essential key, but one that we have only recently begun to focus on. Research shows that a strong

sense of the spiritual in the world helps people recover from any illness. It helps us focus on the big picture and what is truly important. When you get right down to it, faith, hope, and love are the three things that help people like Coleen, Pam, Brenda, and others survive and recover from losses that the diagnosis of a mental illness can bring.

JAN LEE

Consumer

Skyland Trail, Atlanta, Georgia

I went into the Skyland Trail program in November 1997, and by March 1998 was able to move into an apartment. Those four months made a tremendous difference for me. Before entering the Skyland Trail program, I had been hospitalized for depression four times that year. At Skyland, I found many helpful groups, such as horticulture, art,

BOTTOM TO TOP: *Jewell Powell, Kathi Goodwyn, Delois Scott, Coleen Collins, Rosalynn Carter, Richard Lewine, Jeannette DePoy, Jan Lee, Cissy Best, and Richard Van Ingram.*



Q

Questions & Answers
with Panelists

A

How can we work with consumers and families together to head off this constant conflict about the worthiness of medication? We really have a hard time.

Richard Lewine: *The thing to remember is that medication is a process, not a one-time visit or a one-time discussion or a one-time argument. The truth, however, is that we are caught between a rock and a hard place. There is nobody more eloquent than Elfour LaToya to present the case for medication. I think that you simply have to keep trying.*

Over 20-plus years, I have seen people change their minds about medicine. I have seen that people, when given a little space to think, often come to the very same conclusion that you would have tried to force on them. I think the whole effort across the country to speak about medication adherence rather than compliance, speaks to the issue of an attitude. It is an attitude that is critical. Those people who provide treatment have to begin to think differently about offering things that people may choose not to take.

Peoples' minds change. You have to keep working at it.

and music, that were geared to help us express ourselves and get out of our inner worlds.

I also found the attentive care given to our medication to be superb. For example, my counselor suggested to my doctor that we change the time of one of my medications. It proved to be most helpful in getting me up in the mornings.

We had mid-week and weekend outings that helped us to get to know the staff and other clients. These outings resulted in a feeling of family and connection. In my opinion, this second family has been one of the most positive forces behind preventing a relapse.

Equally positive was the dedication and caring of the individual staff toward the clients. The staff's commitment surpasses the job requirements. They make the clients feel important. There is a very caring atmosphere, and genuine acceptance felt by the clients.

This led to my trust in, and respect for, the staff, and motivated me to do my best. In two months, with the help of our vocational counselor, I had secured a job working with children. I have been at that job for 16 months. I have not been in the hospital for 18 months. That is quite a switch from four times in 1997. Both my psychiatrist and therapist contribute it to the continued after-care support and the feeling of connection that we have at Skyland Trail.

I am most grateful to the Lord for a place like Skyland and the people who are willing to dedicate their lives to people who have an illness.

RICHARD LEWINE, Ph.D.
*Director of Schizophrenic Disorders
Program, Emory University School of
Medicine and Clinical Director*

Skyland Trail, Atlanta, Georgia

If I had to put one thing at the top of the list that I think distinguishes not just Skyland Trail, but all of the programs described in this report, it is the character of the staff. We have read about staff's integrity, maturity, dedication, concern

for others, and willingness to work hard. We have read that this is something more than a job for people. I can guarantee that if it were just a job, the pay would be too low for it to be very rewarding.

There is another characteristic, however, that I find extremely necessary, certainly in the staff with whom I work, and that is not being defensive. While we have gotten away from emphasizing weaknesses and problems among consumers and clients, we have to look at weaknesses and problems in staff. It is very difficult to ask one's clients to do more than one is willing to do oneself. We place a great deal of emphasis on looking at our errors, on examining how we do things, and trying to be as supportive as possible.

Looking at one's problems is not easy. It is no easier for staff than it is for consumers, but it is absolutely critical. I would hope that as a follow-up to this symposium, there might be a meeting entitled something like, "Mistakes We Have Made And What We Have Learned From Them." Because as was said by Carl Newman many years ago, "Knowledge rests not upon truth alone, but upon error also." We must be willing to look at our errors and learn from them. Even when our programs are working well, we are not quite sure what is making them work. It is the errors that are often the most illuminating.

The single best predictor of therapy outcomes in many studies is whether the therapist likes the client. What is it that allows one person to like another person and adopt a role of therapist or collaborator? I do not know. I do know that if you do not like the people with whom you work, be they consumers or staff, life is going to be miserable. We could probably all agree on certain characteristics in people that are essential to creating staff with whom we would like to work.

When I make personnel decisions, I expect that someone who is over the age of 20 comes to the job with some degree of maturity, integrity, and a sense of ethics. Hopefully, that is not on-the-job training. There is no doubt that you

can train in listening skills, and a host of other techniques, but the issue of character is critical.

The real challenge, of course, is telling someone that his or her character is not suitable for the job. It is very difficult to do that without creating a reputation as a horrendous person. Firing is not easy.

Another practical aspect of programming is the coordination of services. We frequently have individuals working with us who have been in various parts of the public and private domain. They might have been to three psychiatrists and 10 social workers, but there is no single person who knows the big picture. Without that big picture, you risk a lot of practical problems. We had a recent episode in which one of our former clients was in jail, transferred to a hospital, and ultimately released. We discovered that he was taking only half the dose of the medication that had previously been quite successful for him. Somehow, among all the transfers and communications, that simple fact never was passed from one person to the other. This person had to suffer for several extra weeks until the medication was adjusted properly.

Fragmentation of services and the extraordinary pressure from managed care for quick fixes combine to create numerous service and information gaps. If there is anything that is absolutely essential now, it is for people to have the big picture and to follow a person's life, not just a case number.

We also do something that is probably mildly politically incorrect. We place a great deal of emphasis on the basics. We do talk about medicine. We talk about the illness in a very supportive environment. Sometimes people need to talk about things that they may not really want to. We try to do that in as supportive and as non-judgmental way as possible, but it is essential.

One of the most rewarding aspects of being at Skyland Trail has been that we have unambiguous support for quality clinical care from virtually every part of the organization. From the founder of the George West Foundation, all the way

through the ranks of the organization, there have been times when it would have been expedient and perhaps profitable to have taken a course of action other than what was clinically correct. Never once has that ever been in question. That creates an environment that is genuine.

Finally, family is a critical piece of all this. Community, spirit, connectedness, and relationships are what life is all about. The extent to which we can create that environment, whether through informal facilities, affinity groups, or another means, provides the long-term support for all of our lives. It does not matter whether you call it recovery. What matters are other people and the ways in which you are connected to them. Are people there for you when you are feeling down? Is there someone you can talk to on the phone, even if you are not formally involved in a program? These are the sorts of things that have emerged from Skyland and many other programs in Atlanta. I consider them to be the basis of long-term recovery.

There are two observations that I would like to share. The first is how little we have focused on technology. This is not to say that technology is not important. The technologies of neuroscience, medication, and psychosocial or psychiatric rehabilitation are all important, but we really have not focused on them. This is very significant and it leads to my second observation.

What we have spent a lot of time talking about are values—fundamental values. Coleen referred to fears and demons, which drove her for so long. Her second poem however, talked about dreams, which now lead her into a future. We have heard people talk about competency and character, integrity, and dedication in staff. We have heard about courage, faith, persistence, and hope for consumers. Maybe that speaks to Bill Anthony's vision of a round earth of values, with a new vision leading us into the future.

Q

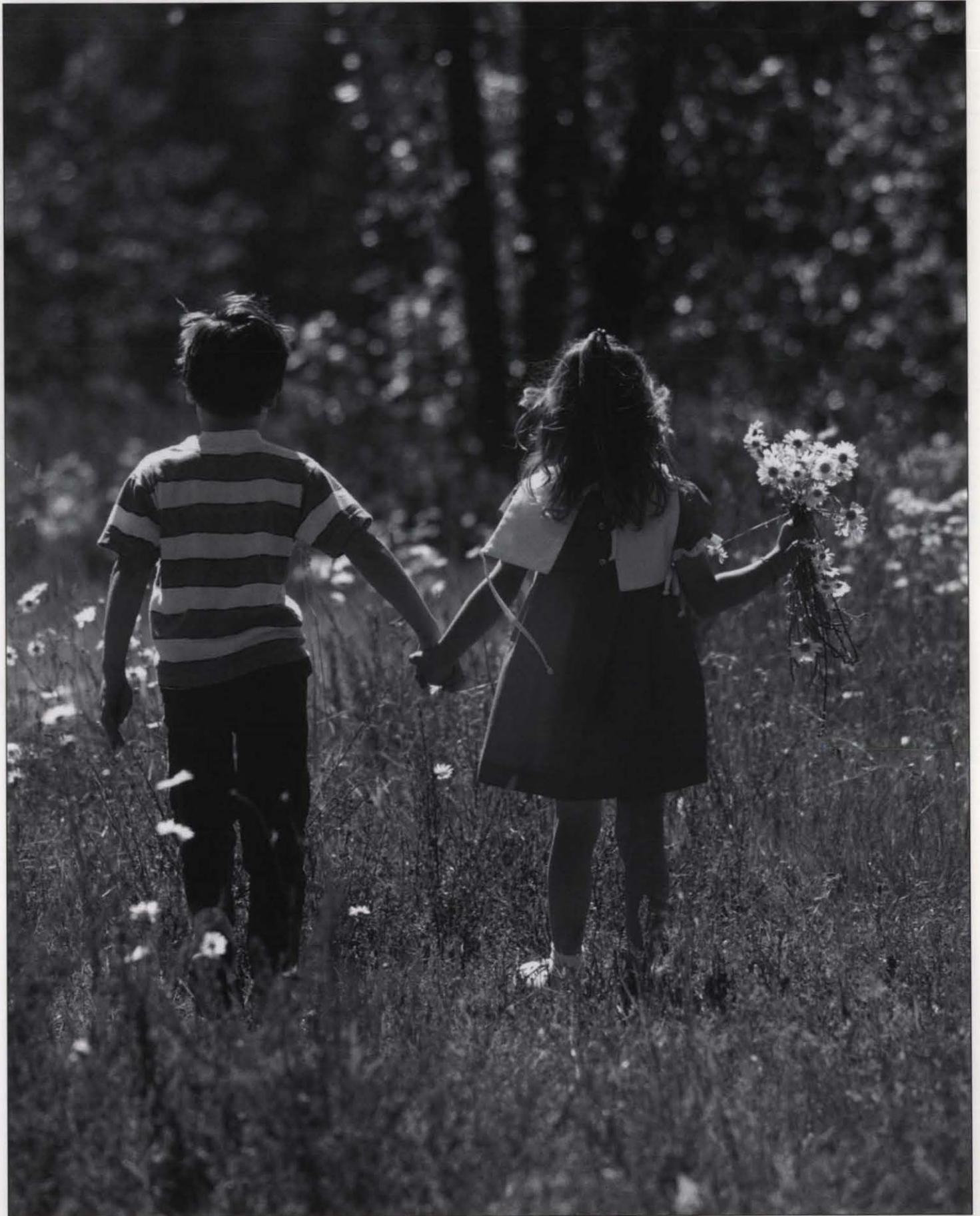
Questions & Answers
with Panelists

A

*Additional answers to question
on page 22...*

Jeannette DePoy: *From consumers at Community Friendship I hear frustration with the listening skills of some of the people who are prescribing the medication. I had a consumer tell me recently that he asked his doctor if he could slightly decrease the medication because it was causing some side effects and some sedation. The doctor gave him a prescription for an increase in medication. We have to look at ourselves as professionals, and as advocates, to help consumers talk to their doctors about medications and any problems. I know that is not all of the answer.*

Jewell Powell: *It does take time and patience. Medications do have to be changed. There is more than one way to medicate patients. It is important that families support one another through the process of making changes and accepting medications.*



Overcoming Barriers to Implementation

Implementing the Medicaid Rehabilitation Option

CHRIS HENDRICKSON
Director, Bureau of Community Mental Health Division of Supportive Living

Wisconsin Division of Health and Family Services

In Wisconsin, we have community support programs to help overcome barriers. The research around community support programs was started in Madison, Wisconsin with the program for assertive community treatment teams in the late 1960s.

The early outcomes of those programs were very positive. They showed that individuals with serious and persistent mental illness could be treated in the community with proper supports and services. Because of that report, we started working with county programs at the state level. Wisconsin is set up in a county-administered system. We have 72 counties; each receives funding from the state that they are required to match for mental health services. The combination of state and county dollars offers a lot of flexibility in how mental health services are arranged and provided. Back in the 1970s there were a lot of funds available and most counties set up these community support programs.

The Medicaid rehabilitation option became available in the 1980s, allowing counties to bill Medicaid for services if

they met certain requirements. Wisconsin was fortunate to have a vacancy at that time in the Bureau of Community Mental Health, which they filled by hiring Deb Almus. Deb, along with staff and others in the field, some consumers, and family members developed standards for these community support programs.

By 1988, those standards were propagated and programs that met them were able to bill for Medicaid. People often ask how our state was able to come up with the money to fund these programs and pay the match for federal reimbursement. Wisconsin told the counties that if they wanted to have a certified program and bill Medicaid for these services they would need to come up with the state match themselves. This way it did not cost the state any additional money. It was a very creative way of using state money that we were already giving the counties as the state match for drawing down federal funds.

That has been very successful. We have about 85 community support programs that cover all areas of the state. Some of the larger counties, like Milwaukee County and Dane County, where Madison is located, have several community support programs. Seventy-eight of those programs are certified and drawing federal funds.

In 1998, the state was able to draw close to \$12 million. It is very significant that a system that is currently under-

The research around community support programs was started in the late 1960s. Early outcomes showed that individuals with serious and persistent mental illness could be treated in the community with proper supports and services.

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Questions & Answers
with Panelists

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Audience: *The rehab option is practical and cost-effective. Yet the people who are providing do not seem to be getting anywhere. Why do people do things that do not make any sense?*

Chris Hendrickson: *The state would have to come up with new dollars. Wisconsin was able to overcome that because of the way it funds its county service system. I do not know whether those dollars are available under Georgia's system.*

What we need to focus on is how we can use the dollars in the current system the way people want to use them. We are not restricted with Medicaid dollars just for inpatient/outpatient day treatment. They can be used for consumer-operated and directed services. That may be an approach you can use as a selling point.

funded was able to put that amount of additional funding into our mental health system.

It is also critical because we are in the process of moving to a managed care system that would capitate Medicaid dollars. We are under strict guidelines that prevent us from using any more Medicaid dollars in the system. This additional \$12 million helps raise the cap rate per individual that will be funded in our new system.

Many people have probably heard that these community support programs are very successful, that they do a very good job of keeping people out of hospitals and institutions. In 1997, only 25 percent of the individuals enrolled in community support programs were admitted to the hospital. Only five percent of the total number served were in the hospital for over 21 days. That is a great reduction compared to the time spent in hospitals or psychiatric institutions before they were enrolled.

Over 75 percent of the approximately 6,500 people enrolled statewide in our community support program are either living alone or with a family member. Nearly 20 percent of them are competitively employed. That is, not in a supportive employment program, but in a competitive job site, either full or part time. Still, we consider that very low. Employment is something we definitely need to work harder on. There are still a lot of barriers to work.

One of the new programs we are working on is modeled closely after the Kennedy-Jeffers bill. We call it "Pathways to Independence." It would allow individuals on SSI or SSDI to work as much as they want, save as much as they want, make as much as they want, and not lose their Medicaid insurance benefits. Five mental health programs in Wisconsin will be involved in "Pathways to Independence."

In 1986, we developed the standards for community support programs. Although many people were involved in the creation of the program, it was not set up as a recovery-oriented service delivery system. We need to look into them.

There are very strict requirements about who is admitted into our programs. They have to have serious and persistent mental illnesses. Once an individual gets into the program, there is not always an easy way out. That is something we need to look at. There are minimum staffing requirements that are effective because they provide a comprehensive, wrap-around approach that individuals want and need. There are however, many individuals who may only want pieces of that program. How will we help them? Over the last 10 years, we have gotten most of our programs certified. We have a number of people enrolled. The outcomes have been very successful.

Where we are going next is based on what we call our bible — our guide for mental health services in Wisconsin. In 1996, the governor created a Blue Ribbon Commission on Mental Health (BRC), which represented all stakeholder groups in the state. The commission's report is shaping the future of mental health services in Wisconsin.

Our mission statement is, "All persons in need of mental health services across Wisconsin have equal access to resources that strengthen self-determination and self-sufficiency by promoting health and wellness, improvement in recovery, quality of life, and dignity."

With that vision, we are looking at more flexible funding through a managed care concept. Over the last year, a number of different work groups, with all the stakeholders, have looked at how we can make this work for everyone.

The BRC recommendations talk about consumer focus, directed services, a recovery-oriented model, choice, and flexible funding that will allow individuals who come into the system and get a Medicaid cap rate along with additional state and county dollars to be able to select from a variety of sources, including consumer-operated and directed services, community support programs, and housing.

We have to know how to offer community support programs with the full array of services. We have to consider the option of taking pieces of that pro-

gram and allowing people to say, "Well, I would like the vocational options that are in there or the medication management, but I want all the other services from someplace else." One way we are doing that is creating a new set of rules, the Comprehensive Community Services Standards with unbundled services. These will also be Medicaid reimbursable. When the legislature asked us to develop these standards, it asked that they be more than outpatient, but less than community support standards. Those rules are in draft form. We hope to have them propagated by the end of this year to allow us another Medicaid option, which will then move into our Medicaid capitated rate system.

The managed-care demonstration sites will begin within the next year. We are hoping to have approval from the legislature to start floor demonstrations beginning in July 2000. These demonstration sites will be set up around the state. This will again be done through county service delivery system. Counties will be the managed-care entity and, hopefully, will begin to fulfill some of the recommendations that have been outlined in the Blue Ribbon Commission report. Again, this would allow a more flexible use of Medicaid funds to ensure that mental health consumers are given choices in the services that they want, how those services are provided, and who provides them.

Psycho-Social Rehabilitation in Georgia

SUSAN ROBINSON

Consumer Employment Specialist

DeKalb Community Services Board

We are not alone. We are part of the world of people who have mental illnesses. The International Association for Psychosocial Rehabilitation Services represents 30 states in the United States and many countries. It has some 2,000 members serving thousands upon thousands of people who have serious mental illnesses. They have been trying for the past 25 years to make services more suitable for people. This does not just affect those who have a mental illness. It affects everyone in this country. There are people in your neighborhood, your family, your church who have mental illnesses. Every one of us can point to people who have struggled and overcome a mental illness, who have finally realized that there is hope in life.

The concepts of psychosocial, or sometimes psychiatric, rehabilitation are not complex. They are very simple because every person's needs are the same. We all need friends, work, a decent place

to live, and meaning and purpose in life. When I go to a service provider, I know it is good if there is a commitment to recovery, if the actions and words are intended to encourage people to have hope and recover.

I had a colleague who told me that he did not want to be involved in the program. He was coming only because if he did not, he would have to move from where he was staying. I said, "Okay, I will accept that. If I were in your place, I might be doing the same thing." I can get extremely stubborn when somebody tells me, "You have to."

I said to him, "All right, then, I just want you to do one thing everyday that you come, just do one thing." He has since gone back to work.

We have thousands of people in this state who do not know how to speak up for themselves. They tend to be invisible. It behooves every one of us to find these people, get to know them, and help them have a voice.

Another colleague of mine said that she went to a program and simply sat for months. She said, "I had to do that, because it was all I could do to simply get there every day." Finally, she said, "I took

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Questions & Answers
with Panelists

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What do you do with those who seem to make little or no progress during treatment?

Susan Robinson: *We have to accept where each of us comes from and cannot pressure recovery. We cannot force it. We have to invite it and encourage it. It will not happen if somebody makes you do it. If the attitudes within a program's walls are hopeful, then there is no apathy. Sometimes there are people who are just sitting around. Sometimes people have to sit. But it is more than that. Even if people are just sitting, are they still being invited to participate? Are they still being spoken to? Is it still recognized that they are there? It is important that they not feel invisible.*

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Questions & Answers
with Panelists

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Do we face other barriers besides the system of funding?

Susan Robinson: *One is the lack of a community-based philosophy. We still have a hospital frame of mind. The money that has historically been funded at the hospital sites has not flowed into the community. As long as we have a hospital mentality in funding, money will not flow adequately into community-based treatment.*

one step. I moved to another chair and that is what began my road to recovery.”

Are staff attitudes respectful or condescending? Are people referred to as the chronics, the schizophrenics, the crazy people, or are they referred to as people we can serve? Do we learn from each other? Sometimes we do not. Is there understanding and empathy? Are we inclusive? Are we trying to have someone work side-by-side with us to do something or are we discounting whatever he or she might contribute? If we hear people make condescending, demeaning, or insulting remarks about people with serious mental illnesses and we let it go by, who are we? We are promoting the stigma of mental illness and we are part of the problem. Over the years, I too have done that. I am not guiltless, but I am trying, all the time, to learn to stand up, be brave, and speak out.

Another thing that I notice when I first walk into a program is whether there is energy or stagnation. Are people interacting with everybody? Do people really want to be there? Are people welcome? Are they missed if they do not come? Is a simple phone call made?

What are the boundaries between staff and consumers? Do we have office doors that are shut and do we have to knock hoping to be invited in? Or do we have an open atmosphere where people have easy access to each other? As Dr. Anthony said, “Do we have staff bathrooms and client bathrooms?” We are all the same. There are certain things in life that we can handle the same way. We can be together, eat at the same table, and use the same bathroom.

Are you trying to include people and be a team? Are you using your coach’s advice? Are you giving encouragement to a team member? To use a basketball metaphor, are you making decent passes to each other? Are you catching the pass when a consumer in your program says, “Maybe I would like to go to work?”

Dr. Torrey spoke eloquently of the number-one barrier that we face when he addressed the U.S. Senate Subcommittee on Finance. He said, “The thought disorder

found in schizophrenia is minimal compared to the thought disorder found in the funding system designed for the care of these individuals.” It is true. I cannot figure it out. I know that somehow there has been a collaborative effort to make this system be what it is. We have done this. We can undo it. We can make it serve who needs to be served. We all know that money is a key factor.

The closest we have come to putting a community orientation on funding was when we had CMI target-area funds. I remember John Gates saying, “This will allow us to take this chunk of money and put it in one place in the state. With that money, we can do something right. Then, we can take the next chunk of money and do something right in another part of the state, instead of giving everybody these tiny little slivers of the pie.”

It really made a difference. I know it made a difference in DeKalb County. It allowed us to do some things that were thrilling, and made a difference in lives. I encourage us to find ways to use money, and get money, so that we can do the things we know are right.

In 1996, Georgia ranked 49th out of 50 states in the percent of funds used for community services. Only 20 percent of mental health funds for community services were actually put into the community.

In other states, it is 50 percent. Some solutions to these problems are contained in a report called *Training in Community Support Systems*. It was written at the Georgia Mental Health Institute under the direction of Martha Hodge and the Community Support Services Team of Georgia. In this document are all of the services that are effective and need to be provided. Seventeen years have gone by, and we have implemented bits and pieces of the report around our state, but we do not have it fully, solidly in place. We could do it now.

We also need to increase training in psychosocial rehabilitation services. We spend 80 percent, maybe more, of our money paying staff, but we have staff inadequately trained to do what their hearts are saying to do. We are throwing money away.

Sometimes things take longer than they should because we do not believe there is a remedy. In this situation, there is a remedy. We have known the effects of psychosocial rehabilitation for a long time. It has been around since Adam and Eve. We know what to do. We need financial reform so we can have flexibility with money. We need to say strongly that we know that services can be improved in the community.

Some of us are in positions of influence and authority. We could act now.

Integrated Services

DENNIS WESTMEIER

Director of Substance Abuse Services

Lookout Mountain

Community Service Board

I am not going to try to tell you all the intricacies of what we have had to do at Lookout Mountain Community Services to approach a real integrated service. There often is an escalation of services, and brief periods of connection between those services. We delude ourselves into thinking that it is, in fact, an integrated service system. Unfortunately, many times it is not. If we do not challenge ourselves continually, and constantly, then lock-step treatment services remain in place. They just look a little different.

We have set and achieved goals for ourselves. Every time we achieve a goal, it is an opportunity to set other goals. Goal-setting seems to be a never-ending process; that is a healthy thing.

Lookout Mountain Community Services is not ready to publish the book on how to overcome barriers while integrating services. We are still learning. In many cases, we take two steps backward before we take one forward.

The important thing is that we are moving, even if amoeba-like. Soon after addressing one of the "seedpod of the amoeba," the amoeba develops another. It is an ongoing, exciting — albeit frus-

Others of us are not in those most key positions, but we have voices, energy, and talent. All of us know what is right to do.

In this state, psychosocial rehabilitation falls mostly within day treatment programs and residential programs. It needs to be spread into all our services. Everyone — the director of the center, the psychiatrist, the families that bring their loved ones in, the people that drive the vans — need to know what it is about and how to do it.

trating — process.

We started with the staff, with the support of the executive committees, boards, and directors. We had competent, though somewhat resistant staff.

We had to overcome some turf issues. *My patient, my client, my consumer, my program, my office.* I am encouraged by how well the staff has come together as a true treatment team. They are beginning to find relief from having to be "Lone Rangers." They appreciate not having to be the universal expert in every possible thing that might come up.

We have worked diligently to help the staff see that individuals come to us for help, with a myriad of difficulties. These problems are not mutually exclusive. We ourselves are complex human beings. It is important to see that what before may have been considered ancillary difficulties, or bumps in the road, are in fact, an integral part of what makes a human being the way he or she is. Substance abusers generally do not present themselves as pure substance abusers. There are other factors in play. Some were in play before they began using; for some it is a way to self-medicate.

For years, substance-abuse professionals were very insular. They had an unhealthy view of the psychiatric community. They were suspicious of social workers because they felt that they were the only ones who could deal with substance abuse. That attitude has dissipated over the years, but there are still elements

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Questions & Answers
with Panelists

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How did you handle staff members who resisted the changes you felt necessary?

Dennis Westmeier: *I have never considered resistance unhealthy. Change creates resistance. Very few of us are foolhardy risk-takers all the time.*

There is a distinction between resistance and defiance. There is not much you can do with defiance. But resistance is workable. We worked together to find ways to implement the changes that we agreed were important.

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Questions & Answers
with Panelists

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What was it like to be offered a job after years of being unable to hold one?

Marie Watson-Allen: *When this job as coordinator with the Albany Area Community Service Board for Consumer Affairs came open, it was as if God had opened a door for me. I was about five years clean and sober, and I knew that I wanted to do something to help somebody that might be in the same position I had been in. But I did not know what I could do. Everywhere I had ever worked, my past was a liability. This job came open and it was as if God opened the door. I just kept walking through the doors. My past is no longer a liability; it is an asset. That is the most God-given miracle in my life.*

I knew one person who did something like what we were going to do in south Georgia. I came to Atlanta and spent a week with him, and met all these wonderful people. I went back, and was totally overwhelmed. We made a lot of mistakes. But we learned a lot. The learning curve was very high.

of resistance. Some have said, "Sure, substance-abusing people are diagnosed with depression because of the withdrawal that they are experiencing." Sometimes that is true, sometimes not.

We address these problems by improving our services. Services that are very discreet often keep an individual in a continually vulnerable position, an extremely dependent posture. They have nowhere to go. If they develop continuity in a relationship, this also makes them dependent. It places them in a vulnerable position because they are not taught the skills to live productive, efficient, and effective lives.

We have to let individuals be the hub of the wheel, rather than be crippled by diagnostic considerations. We should not ignore diagnostic considerations. We should not belittle them. We need to address them.

However, sometimes we treat a diagnosis and forget that there is a person sitting in front of us looking for help. We need to use the services required to resolve a problem as only one of the integrated services that we provide. It is not the core of it. The individual should become the core of our concern.

The Joint Commission on Accreditation of Healthcare Organizations and the American Hospital Association have required that an individual be able to demonstrate participation in the development of a treatment plan. I am learning to call that "an individualized services plan." Very often, clinicians would try out a treatment plan that had been signed by 'x' person. Many times, they were just asked to sign. We have to actively involve the individual in the identification of his or her own problems, needs, wants, and preferences. I believe that those who come to us for services know what they need and want. The problem is knowing how to access it.

This also gives the counselor, or therapist, a chance to collaborate with the individual, who may be short-sighted, or not know exactly what might be available.

We established programs based on what consumers were telling us. We used client input to set service expansion

goals. Without that information, we would have maintained an atmosphere in which we identified what we thought the consumer needed and just hoped that it fit.

To accomplish this, we had to develop an extensive list of resources available within the community. We had to do a lot of soul searching to develop programs and approaches that were not readily available. We cover a fairly large area. A lot of services are not available in our program. We had to expand our services and develop a continuum of care so that individuals are not stuck in any one place for an extensive amount of time. There are step-downs, there are step-ups, and there are step-arounds. We have training centers where people learn skills. We have supported employment programs. All were developed because of the recommendations, needs, and preferences that consumers identified.

We try to be as inclusive as possible. In the past, families were often seen as add-ons that at times interfered. If that happened, it was because they did not understand. We have an obligation to help them understand, so that they too can have a sense of reunification of the family system. Whether or not the individual returns to live at home, the emotional connection is extremely strong and needs to be supported.

We also had to look at our assessment instruments and make them less interrogative. Many times in bio-psychosocial histories, all you needed was to turn a lamp on people's faces and ask a series of questions. We would tell people, "We have ways of making you tell us what we need to know." It set up an almost adversarial relationship that sometimes carried over into the therapeutic experience.

There was specific data we needed. By asking open-ended questions, and allowing the consumer to give as thorough an answer as he or she can, we gathered much more information and data than we ever would have using an interrogative style.

After we gather all of these assessments, various members of the team would come together. We start discharge

planning at that point. Discharge planning is not necessarily a discharge to leave the program. It is transitional planning. When, and under what circumstances, can we transition this person to another level or type of care? What kind of care would we provide the person with the least restrictive environment to deal with immediate problems, while simultaneously being able to move on with his or her life? That may be through supportive employment programs, living in a group home or a crisis home, independent living arrangement, or simply going on with his or her life just as I go on with mine. We are seeing positive feedback and results from many consumers. They feel as if they are being encouraged to go on with their lives as those of us who think we are normal do. Normalcy is determined by the person who is describing it or the person who thinks he or she has it. Consumers are able to see themselves doing some of things that the "real world" is doing. We cannot keep these people in cocoons for the larger portion of their lives.

We had to help the staff, ourselves, and the consumer realize how to access services available internally. We had to

provide consumers the opportunity to access resources in the community. Community-based resources are the real world. The sooner that we can get people involved in their community, the greater the progress they will make in the quickest amount of time.

The hub of the process is case managers. This term means many things, and has been defined in various ways. Case managers are not passive participants in the process of health care delivery. They do not merely shuffle people between programs. A dispatcher from public transport can do that.

The case manager is an active member of the treatment team. Case managers enable and objectively assess progress being made. They participate in the setting of transition times. In advance, they meet with the consumer to set out the plans that he or she would like the case manager to have in place. All of that sounds rather ideal, and it is. It is not working as well as I would like. But it is working. I will take one piece of the loaf of bread and hope to get the whole loaf.

The important thing is that we are asking questions. We are challenging ourselves. We are not satisfied with what

LEFT TO RIGHT: *Jean Toole, Susan Robinson, Chris Hendrickson, Dennis Westmeier, Roger Scott, Rosalynn Carter, Marie Watson-Allen, Robert Lowrey, Elaine Robinson, Earnestine Pittman*



ROB GALER PHOTO

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with Panelists

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Patricia Thacker: *I am a substance abuse counselor. I would like to address two earlier questions, that of a young lady who asked how she could get her therapist and her doctor to help her, the other from a man who told his doctor that his medication was too strong and the doctor upped the medication.*

If you have a problem with anyone at your service center, first go to the director. If the director will not listen to you, get the 800 number for the consumer advocate office and call it. If that does not help, get the names of the people on your Community Service Board and call each of them. If that does not help, get the names of the people on your Regional Service Board and call all of them. By that time, someone should be asking, "What is going on at that place to cause this person to call me up?"

You will stir things up.

As a consumer, or as a consumer family member, talk. Do not keep it a secret.

Also, when someone says, "I am not going to take this medication anymore," I say, "That is your choice. You have the perfect right to not take your medication." At first, he looks at me like I suddenly sprouted two heads. But he is relieved. He has some control.

we see and what we get. There are more things out there to accomplish. That determination and that accessibility is rubbing off onto the consumers with whom we work. They are beginning to require things. They are beginning to state their needs. They are beginning to ask for things that they did not ask for before. They just came, and sat, and did what you asked them to do. It is an encouraging beginning.

The last barrier is transportation. I am from Boston. When I first came here, I was waiting on a main street for the bus to come. It was a good thing that someone was kind enough to tell me there was not one, because I would still be standing there, and I have been here six years.

Getting consumers to and from programs and services was a great challenge. Fortunately, Lookout Mountain Community Services has an elaborate van/bus system. In fact, we provide bus

service for people in Walker County. The only thing we do not have is the token box. It is wonderful to be able to get consumers to programs who could not otherwise get there. It is an eye-opener to be able to tell a consumer who lives in Rock Springs and cannot get there, "Good, we will come get you." At least, it makes her think of another excuse. No matter what good things we might have available, if they are not accessible, it is the same as not having them at all. We have dispatchers to transport people to and from the doctor.

We provide medical monitoring, administration and education. These things are coming about as we integrate services so that a person can move through the system without getting locked into it. The goal is to allow a person to walk out of our program, head up, chest out, proud, and ready to take their place in society.

Outcomes and Evaluation

ROGER SCOTT

Director of Quality Management

Georgia Mountains Community Services

The subject of outcomes evaluation is certainly not a new one for health care. For mental health, mental retardation, and substance abuse systems it has become increasingly pertinent over the past decade. Several factors have brought this increased attention and importance to outcomes evaluation.

A newspaper article a couple of years ago conveyed the increasing importance of outcomes evaluation. An influential politician at the time was quoted explaining why he supported a budget cut for certain health care programs. He said, "I am not willing to continue to support funding of these programs because we have no idea what we are getting from these programs."

That was a significant barrier to our progress in continuing to provide an adequate service system. A recovery vi-

sion demands that we do a better job. Outcomes evaluation systems are important. Some would say they are vital to the survival of certain programs or providers in behavioral health care.

Managed care is with us. There is no indication that it will go away. A recent article on managed care caught my eye. It had an interesting title that I would also apply to outcome evaluation: *Now that we have managed care, how may we inspire it?* Now that we have outcomes evaluation, how shall we inspire it? We do need to inspire it to continue to improve the quality of our services as well as justify the continued support of taxpayers and the persons we serve. It is a part of maintaining trust.

Barriers to implementing outcomes evaluation systems are coming down rapidly, but perhaps involuntarily. Many committed and dedicated providers have already been evaluating outcomes in systematic and credible ways, and would have maintained the commitment to do so without external pressures for account-

ability. It has been two years since I was hired to develop outcomes management services at Georgia Mountains Community Services. I was given a job description that involved preparing the agency for accreditation and responding to increasing external demands for data on the effectiveness of our services. I have encountered barriers and we have worked through them fairly well. It has been a learning process.

Professionals and service providers have an inherent resistance to being evaluated. That it is just human nature. No one likes to be evaluated, including me. It is a threatening process. However, being constructively self-critical is a crucial feature of an organization committed to continuous improvement.

This more benign form of internal evaluation functions as an information system that supports continuous learning. It helps identify not only errors, but also unfavorable outcomes that were due to lack of knowledge. Maybe a better way has not been found yet, but we can use this information to find a better way. As a program is implemented in that spirit, it can be successful and barriers can be minimized.

There are certainly technical problems with implementing a good outcomes evaluation system. It is not a cost-free process. But those barriers would be better characterized as challenges and challenges are not insurmountable. We have learned a lot about program evaluation over the past 20 years. There are more and more tools — imperfect but adequate — available to resolve technical problems associated with outcome evaluation.

Including staff and consumers in designing outcomes evaluation systems is an important approach to reducing attitudinal barriers and developing a system that is really useful.

The best approach to working through attitudinal barriers is to be able to demonstrate that the systems will produce useful data that can be translated into tangible improvements in service quality. That is the challenge. Another is in using the data in a non-punitive way to bring about a positive learning environ-

ment and a continuous quality-improvement atmosphere.

The data of outcome evaluations are a preface to a discussion of the details of our system. What is quality? Outcome is one important aspect of quality. The process of care — the best practices for producing the best outcomes — is also an important part of quality.

Although there are many dimensions to quality, there are three that are most important for an adequate evaluation system. The first is consumer satisfaction. This involves having a systematic way of getting meaningful input from consumers. It is not just giving the service providers a report card, it is also providing substantive recommendations for quality improvements.

The second dimension of quality is measuring the impact of our services in improving the lives of people we serve. What is the difference between consumer satisfaction and effectiveness of services? Consumers can be very satisfied with services, but those services may be having little impact on the quality of their lives. They may be satisfied with their relationship with their provider, but little may be changing. They may feel they are treated well, without making substantial progress in improving either the objective or subjective quality of their lives.

The third dimension of quality is value, or the cost of services. This relates to how efficient we are at providing services. That tends to be a sensitive point, because most agencies take the position that they are under-funded. If we need to advocate for additional funds, we should be able to demonstrate that we efficiently use the funds and resources that we have.

Here are some some key points in the technical aspects of designing quality improvement systems. People who are developing systems, or are continuing to improve their systems because Continuous Quality Improvement (CQI) applies to their information system, should be continuously evaluating the quality of the information. Is it useful? If not, you need to make changes.

Measure things that are important to consumers. Choose tools that give

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Questions & Answers
with Panelists

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I suffered from chronic, severe clinical depression for 35 years. I spent much of that time in my home, totally isolated, not knowing what to do. Why do we not see advertising about mental health programs and services that are available in the mainstream?

John Gates: *We have all been fighting for so long to reorient professionals, public officials, and the entire community to be sensitive to people's suffering, and to provide outreach services.*

I suggest two reasons for the present situation: money and stigma and discrimination. There has not been a lot of money to be made in treating mental illness, except recently in the private sector. Why are people paid big bucks to talk about Viagra? Because the pharmaceutical companies can make an enormous amount of money if people become aware of it.

The other thing has been the stigma and misunderstanding. Organizations — the National Alliance for the Mentally Ill, the National Institute of Mental Health, for example — are making tremendous strides in creating public awareness.

Of course, public figures like Rosalynn Carter have been bringing this to people's attention for years.

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Questions & Answers
with Panelists

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Elaine Richardson: *Where have we improved? We have more responsible consumer leadership. We have seen communication barriers break down between consumers and staff. Service improvement will always be like recovery: it is an ongoing process and it never ends. If you get to a place where you are satisfied, you have messed up.*

We continue to grow in the number of consumers. We have programs for post-partum women. We have a dual-diagnosis program. We have opened two self-help centers, which the regional board has funded. One is in Albany; one is in the Georgia Pines area.

accurate, reliable data. Produce data that allows comparisons over time and with other providers. Be economical. Minimize paperwork. Do not divert resources from direct care unnecessarily.

Community rehabilitation outcomes are focused mostly on improving quality of life by measuring things that are generally referred to as "objective measures." Are hospitalization rates reducing for persons served? Is their housing status improving? Is their employment status improving? Is their financial status improving? Are they victims of crime or having trouble with the legal system themselves?

There are also subjective indicators to consider. Are they satisfied with their lives? Are they gaining self-confidence, and a sense of independence?

It is critical to understand how the data is used. First of all, consumer-satisfaction data is not just about numbers, it is about people's opinions of your services, and that can be most useful information. Even if 90 percent of consumers are satisfied, your greatest opportunity for improvement is to look at what the 10 percent who are dissatisfied say.

We challenge our programs to develop quality improvement projects each year. We ask them to find the one area, given the resources that they have, in which they feel they can make the greatest improvement and get the best outcomes. Then we implement that. We evaluate again to find out if it produced the result that we thought it would. Over time, you can see progress.

A vision is not obtainable. It is something that you continually strive for. The outcomes evaluation system should give us benchmarks to determine if we are making progress.

ROBERT LOWREY
Chair

Georgia Mental Health Planning Council

The governor of Georgia signed House Bill 100 in 1993. House Bill 100 changed the mental health, mental retardation, and substance abuse systems

in Georgia by creating regional boards. Consumer-satisfaction surveys were one element of what the regional boards were supposed to do.

At that time, I was on the Georgia Consumer Network board and we decided to do a consumer-satisfaction pilot program. With grant money, we started the Georgia Evaluation Satisfaction Team (GEST).

After the pilot, we repeated it in other regions, including my own. We have a large region that includes 14 counties.

We decided that the G.E.S.T. process needed to be changed a little to work in our region, so we came up with a consumer-outcome satisfaction team. Marie was working with the Albany Area Community Service Board at that time and they offered to give her to us for a little while. That was four years ago. She will discuss some of the barriers that we have encountered with the actual process.

MARIE WATSON-ALLEN

Consumer Affairs, Consumer Outcomes Satisfaction Team

Albany Area Community Service Board

I was hired as a Consumer Affairs coordinator for the Albany Area Community Service Board. Not long after I was hired, the regional board decided to implement the Consumer Outcomes and Satisfaction Team. We did not even have a name yet. It was like flying a plane while you were building it.

A planning group was identified that consisted of consumers and family members from mental health, mental retardation, and substance abuse areas, as well as regional board staff. They were convened to develop the consumer survey process.

The G.E.S.T. representative trained this group and we participated in a pilot survey in a mental retardation service center. We found that the survey instrument did not work for that particular population. So, we restructured the original survey.

The Consumer Outcomes and Satisfaction Team was established from this work. We call it COST. We feel that making services COST-effective means putting consumers first.

When the Consumer Outcomes and Satisfaction Team was established, 22 consumers and family members were trained to administer the surveys. They were trained to interact successfully with consumers and staff, and to use observation skills in reviewing facilities and programs.

ELAINE RICHARDSON
Consumer Specialist, Consumer Outcomes Satisfaction Team

Georgia Pines Community Service Board

The first year of the COST surveys, the interview teams interviewed over 1,000 consumers and over 180 staff in three months. In a large metropolitan area like Atlanta, that does not sound impressive. However, we were dealing with 14 counties tucked into southwest Georgia. Those counties are sparsely populated and a very large percentage of that population is below poverty level. People had difficulties even getting to the sites where we interview. When you consider all of those factors, it is a very impressive achievement.

During my history of mental illness and alcoholism, I had hospital staff, physicians, therapists and a friend who refused to give up on me even after I had given up on myself. Shortly after the first year of COST, I lost a career that I had had for 20 years. I had fought my bipolar disorder for many years, even though I had been clean as far as my substance abuse and alcohol was concerned. I had not had a drink in about five or six years. But I continued to struggle with instability with the bi-polar disorder. I can identify with what was said earlier: "I am not bi-polar. That is not my name. My name is Elaine."

Finally, in 1994 my doctor insisted

that I leave my career. I was devastated. Along with the instability I was experiencing, the devastation of losing my career put me into a hospital, where I stayed for over a month. That was about my eighth hospital stay. My friend started calling and badgering me. She just said, "Okay, Elaine, you can do it." Finally I said "Okay" just to get her off my back and prove her wrong. Well, the joke was on me. I was able to do it and went to work for the Georgia Pines Community Service Board.

I was not able to work everyday. I could not work all day, but I was assured that the health of the consumer took precedence over anything else. We consumers met our doctors' appointments and our therapy appointments. If we were having a bad day, we got in trouble if we showed up for work. That took so much stress and pressure off that it really improved our performance.

I benefited by gaining a new sense of identity. I like my new identity better, to be honest. I am not like Stuart Perry, was glad that he got the illness. I think that is pushing it. But I praise God that He has allowed me to find a way to use my illness. I am one who needs a purpose for everything. I want everything balanced in life. God, in His grace, has shown me how I could turn something that was tragic into something very positive. It has made me a better person. It has humbled me. I do not love consumers; I am in love with consumers.

I was on the Community Service Board for a few months when Georgia Pines decided to follow the lead of the Albany Area that created Marie's position, and create a similar position. I wanted that position, but I was scared. If I had suffered another failure, I could not have stood it. But I knew I had to try. I was offered the position and took it. I have been there for two years with no hospitalizations. I am the most stable I have ever been. I am not going to say I will never have another hospitalization, but right now I am feeling good.

Q

Questions & Answers
with Panelists

A

Elaine Richardson: *May 4 was National Depression Awareness — Children's Day. The NMHA sent faxes the morning after the tragic Colorado shooting that discussed how to work with children and pointed out issues related to problems of violence. I mailed this information to every school in Thomasville and Thomas County.*

I heard back from only two schools. Two parents called. Their children had brought home the information. Students told me they learned that others were taking the same medication they were, not just ritalin, but anti-depressants or other mood stabilizers.

We overlook ways that we can erase stigma and ways that we can educate. I always use the term bi-polar so that I can see the blank look on somebody's face. Then I say that it is the same as manic-depressive illness. We need to look for things that others hear and stumble over, so that we can break down the stigma barrier.

I was very disappointed with the response I got from the schools. The school system and the board of education are very much in denial about the brain disorders of children.



Summation

By JEAN TOOLE
*Chair, 1999 Georgia Forum
on Mental Health
Executive Director, Community
Friendship, Inc.*

After listening to our presenters, it is obvious that both nationally and locally, programs and services that support recovery are needed because they are effective. Throughout the presentations, certain themes keep popping up. One of those themes is that in successful programs, people listen. They listen to consumers. They support them in obtaining the things we all want: jobs, places to live, family, friends. We also have heard about the importance of peer support. It is easy for us as staff to think that we have all the answers, but we do not.

Another theme is the importance of family members in this process. Family members are key for all of us. We cannot ignore this. Another key to successful programs is that they provide opportunities for the people they serve to grow and learn. As Dr. Anthony said, "One of the big things about recovery is that it helps people find a purpose and a direction in their life." These people are no longer defined by their illness because they have roles and responsibilities. They have jobs, they have duties, and they are optimistic about their future.

These programs have environments where people are involved and have choices. People are recognized as unique individuals. They are not lumped together. They have created environments where hope lives and where hope thrives.

Q

Questions & Answers
with Panelists

A

Jean Toole: *We have heard about overcoming barriers. Let me remind you what they were: Money, particularly Medicaid money, and how to get the money flowing in the right direction. It has been done elsewhere. We have not been able to break through in Georgia.*

Some attitudes are barriers to overcome, but again it has been done. In Georgia, there has been tremendous progress.

Getting people the right skills is another barrier. Retraining in the latest, most effective techniques can be done.

Uncaring people are hard to change. We have all seen people serving in the system who did not have compassion. That changed when they saw what was possible with the quality of life of the people they served.

Lack of choice was a barrier, but we are learning how to give people more choices.

The power of having good data to use with elected officials cannot be underestimated.

These barriers can be overcome through organization and technology, but also through faith, courage, hope, and perseverance. To quote Winston Churchill, "Never, ever, ever, ever, ever give up."

One of the most critical themes heard today is the importance of staff. It was mentioned in every presentation. A caring staff, composed of people who bring their heart to work, makes programs successful.

There are barriers to implementing these programs — and ways to overcome those barriers. We have learned about the Medicaid rehabilitation option; we cannot ignore this in Georgia.

We need to think about staff training. We expect staff to help people rebuild their lives, yet in many cases we do not provide them with the tools that they need to do that. We have to teach staff it is okay to relate, with warmth and compassion, to the people we serve.

Those of us in leadership positions have to think outside the box, even though it might feel like the box is closing in on us. Dr. Anthony discussed the importance of vision in tough times.

Vision is the string you hold on to while you try to get a good grip on the rope. As leaders, recovery must be part of our vision.

Our programs must be creative. If we ask, "What is wrong with these consumers because they do not like our programs?" we are approaching the problem incorrectly. We need to assume responsibility. If we are not working effectively with people, what can we change?

Another of today's themes is out comes. No longer can we just tell a great story about a person who was successful. We have got to have some numbers to back that up. We have got to show how effective we are. Consumers are important in measuring effectiveness and satisfaction.

We will go to work Monday morn-

ing, for most of us back into our normal routine. Please think about some things you could do differently to improve your program or yourself.

Do we talk about people being unmotivated? Do we have separate bathrooms? Do we describe people as high-functioning or low-functioning? If you do, think about what you can do Monday morning to start a culture change within your organization.

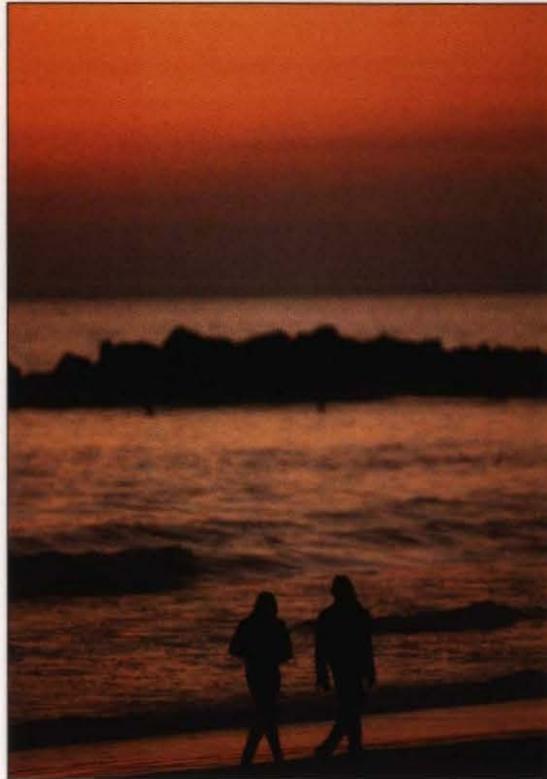
What can you do to become a better, more caring person? How would the consumers where you work describe you? How would the staff describe you? If the words "caring" and "heart" are not there, you need to re-evaluate how you talk and how you act. Do you take people's dreams away? Do you say they have unrealistic goals? This is one of the biggest disservices that you can do.

We are people's cheerleaders. It is important that we be able to inspire others. But it is hard to inspire others if you are not inspired yourself. You cannot be a good cheerleader if you cannot find your pom poms. You have got to be able to find those pom poms inside yourself. What can you do to pump yourself up? Every place you work has people who are negative. Stay away from them. Do not let their pickle juice get on you. Hang around people who are positive. Use language that is positive and encouraging. Create a culture where you do not allow negativity to happen, where people who say something negative about a consumer become outcasts, where people will say it's not okay to talk that way.

How can you grow? Join the Georgia chapter of IAPSRS, a group of people with common values and vision. Come to conferences like this. Read an article on recovery.

*"There is a revolution brewing in mental health. ...
not a revolution in brain science, nor in medication; a different revolution,
the most important revolution, a revolution in vision."*

William Anthony



National Mental
Health Association
of Georgia
Atlanta, Georgia



Georgia Parent
Support Network
Atlanta, Georgia



The Georgia Mental
Health Consumer
Network
Georgia Mental
Health
Consumer Network
Atlanta, Georgia



The Carter Center
Mental Health
Program
Atlanta, Georgia



NAMI Georgia
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Georgia