

Consumer and Advocacy Perspectives

- ♦ What do our patients think about their care?
- ♦ What can advocates tell us on behalf of patients and of persons who need treatment?

Editor's Note: To encourage attention to medical errors in psychiatry, *Psychiatric Services* introduced the Patient Safety Forum in December 2003. Expert discussants are invited to address important questions in this area. Benjamin Grasso, M.D., is guest editor of the forum. Contributing to this month's forum are Virginia Green, a mental health care consumer; Carol Carothers, executive director of NAMI Maine, and Peter Driscoll, M.S.W., director of Amistad, Maine's largest peer support and recovery center; Dollie Hunt-Wilson, another consumer; and Christine Siegfried, M.S.S.W., and Jenifer Wood, Ph.D., of the National Center for Child Traumatic Stress.

A Consumer's Ambivalence

Virginia L. Green

Teeth on edge . . . biting fear . . . suicide talk exposes thin veneer . . . holding on for dear life scratch the dear, scratch the life . . . simply holding on because I think because I must think—I must daren't say what's on my mind . . . too risky . . . trade off truth for survival because I feel I must . . . against the pain of the here and now eternity scores—to lose the battle is to lose the war.”

This is a three-year-old excerpt from my diary, written after a group session in which another patient spoke of feeling suicidal. The discussion made me aware of how often I felt suicidal and how few individuals there were with whom I would share those feelings, which I sometimes did not share at all. It felt unsafe. My words pass through many prisms. And I often felt honesty might keep me in the hospital yet longer.

I am asked to give my viewpoint on psychiatrists and, in my mind, their “trickle-down effect” on the entire mental health system. This is a topic

of ambivalence for me. I have been treated in my lifetime by fewer than five excellent psychiatrists who have been decent and well-meaning, but, unfortunately, a majority of psychiatrists have done more harm than good. This observation extends, particularly in a hospital setting, to those they ultimately supervise—social workers and nurses, mental health workers, and security guards. Security guards? Yes, because if the doctors don't run the hospital with values and honesty and courage, then they accede to bureaucrats who, most often, have political and personal motives and agendas. The vast majority certainly do not put the patients first.

Sadly, neither do a majority of psychiatrists, in my opinion: By putting themselves above the patient, by believing they know more about a person than the person him- or herself does, by seeing the patient as a diagnosis dragging an impaired impersonality, and by not truly listening,

psychiatrists reinforce their own beliefs about themselves and their skills and rarely come to know the human who has become the patient.

The attitudes and the jargon extend from top to bottom. Recently, I sat with an intensive case manager from the state and a paraprofessional from the community agency that was overseeing my care. I was asked to give them early and progressive warning signs and to tell them what helped. I began by saying that the one thing most important to me was to be listened to. After being asked a question, I was interrupted by the two of them talking between themselves. As a person with bipolar illness, I told them about early warning signs. When I was asked about progression, I mentioned racing thoughts and pressured speech. The case manager wrote “transitional thinking.” When I said that was not what I meant, she replied, “Oh, that's the word we use.” It meant nothing to me. I think all people progress through their days with “transitional thinking,” and it did not fit the description that I felt it was important for the staff to watch for.

These are two women whom I genuinely like. Still, they were neither able to really listen to me or able to reflect my concerns and myself.

While I was in the hospital, we had bimonthly “treatment team meetings.” During my long stay, I had only two doctors who in any way asked me to participate in creating my treatment plan. When I had met a goal—which had been established by others—I was rarely complimented; I was simply given three new problems already established by the team. I was rarely asked whether there were problems I wanted to work on. I was

rarely asked my goals. My family was never consulted.

After I had had a diagnosis of bipolar disorder for more than 30 years, the doctor who treated me before my first discharge removed the diagnosis from my chart and said I had personality disorder not otherwise specified. Consequently, I was discharged without being on proper or sufficient medication. Although there were contributing factors to my becoming ill, some my own fault, I returned to the hospital fully manic and psychotic within six weeks. I largely attribute that failure to an incompetent doctor and to another who did not take the time to listen to me, including listening to my conviction that I have bipolar disorder. I know myself and life's

experience well enough to feel certain of that.

I sound less and less ambivalent to myself. I do believe that it is a "we" and "them" mentality that keeps a majority of mental health providers of every rank from the healing ability to connect with a human being. However, I want to temper my words by stressing that there have been wonderful professionals and paraprofessionals who, over the years, have listened carefully, who have responded to me as a whole person, who have genuinely cared for me. I honor and thank them. "Caring is the greatest thing, caring matters most." These were the last words of Fredrich Von Hugel, who was born in Italy in 1852 and died in England in 1925.

equal . . . like I was worth sitting on the floor for."

The responses to the memory question were very powerful, too. The answers were usually short, and included these phrases: "being locked up"; "I lost a piece of my soul"; "always being scared"; "I was a freak"; "I lost hope", "dismissed"; "I was a non-person"; "they controlled me."

All this reveals much about our current mental health system and peoples' relationships with their care providers: Most important? The human element. Most remembered? The loss of power and sense of self. In a field dedicated to taking care of others, we need to go back to our basic sandbox skills: listening, being kind, believing the best of people, and not talking about them behind their backs.

Sally Zinman's keynote address at the National Mental Health Consumer's 2000 summit sheds further light on the system's impact on the people it is designed to help: "It's a battle for our rights and to maintain what we've gotten so far and not go backwards . . . I'm talking about the thrust and movement that is steam-rolling across the country, to increase and expand forced treatment, including outpatient commitment, and all the things that go with that, all kinds of force and coercion . . . There are two trends that are going on, and they're absolutely opposite . . . state governments are talking about recovery, that people do recover, that they can get totally well . . . that life is not just about maintaining yourself in a board and care home on medication for the rest of your life."

E. Fuller Torrey's movement for forced treatment laws adds to the ongoing tension, sometimes pitting families and psychiatrists against people with mental health issues. In the draft report from the Force and Coercion Dialogue sessions, Zinman, speaking for people with mental health issues, says consensus was reached that outpatient commitment would not be necessary if there were appropriate community services available, noting too that forced treatment drives people away from seeking voluntary treatment. The American Psychiatric Association,

An Advocacy Perspective

Carol Carothers

Peter Driscoll, M.S.W.

This country has a long history of tension between people who receive mental health treatment, their families, and the providers who treat them. Books like *Mad in America* (1) and *Diseasing of America: How We Allowed Recovery Zealots and the Treatment Industry to Convince Us We Are Out of Control* (2) offer compelling descriptions of how the medical model can and has harmed people with mental illness and those with co-occurring trauma or substance use problems and their families. A 2003 NAMI report, "Shattered Lives," indicates that between 30 percent and 50 percent of people who are able to obtain treatment services "found serious problems in terms of access, timeliness, quality, and safety."

"In Their Own Words," a report of the Maine Trauma Advisory Group, provides additional information about how people receiving mental health treatment feel about it: "misdiagnosis is common; the way questions were asked was impersonal, cold and intimidating; you have to tell your story all over again and again, even within the same institution; diagnosis puts a person in a box;

trauma diagnoses are used to refuse to provide treatment; trauma symptoms are misinterpreted."

Daily contact in a low-barrier, friendly setting with many individuals who receive services from the public mental health system teaches us that the major issues confronting these individuals in the system are an utter lack of power; lack of respect and kindness; and a shortage of belief in the possibility of recovery. A staff member of Amistad, Maine's largest peer support and recovery center, recently interviewed 36 graduates of the state mental health hospital about their experience. Former patients were asked, among other things, "What was it about staff that made them helpful to you?" and "What was your strongest memory of hospitalization?" The overwhelming responses to the first question included the words "listening," "genuine," "caring," "kind," and "concerned." Typical answers included, "He instantly made me feel there were better times ahead"; "He seemed to genuinely care"; "If I was sitting alone, she would sit with me and talk"; "She sat on the floor . . . next to my bed . . . she made me feel

however, has published a briefing paper calling for stronger community commitment laws across the nation. And, although it recognizes that “40 percent of individuals with severe mental illnesses are not receiving treatment,” the solution identified is not to make services more accessible and responsive but, rather, to strengthen involuntary commitment laws.

Mistrust, divergent assumptions, and failure to respect and value service recipients contribute to poor care, poor outcomes, finger-pointing, and, as noted in the President’s New Freedom Commission report, “Instead of ready access to quality care, the system presents barriers that all too often add to the burden of mental illnesses for individuals, their families, and our communities.”

Modern psychiatry is another of the casualties of the present system. Often, it is a medication assembly line, with people seeing their psychiatrist for 15 minutes every 90 days. Psychiatric caseloads often exceed 100, and billing procedures hinder the development of personal, high-quality relationships that allow listening, choice, and respect. New cost-containment efforts that restrict access to needed medications negatively affect the provision of care while adding to the administrative burden on psychiatrists and leaving people without the medications they need.

The above illustrates the growing gulf between psychiatry and the people who receive psychiatric services, between quality and affordability, and between collaborative care and care that is impersonal and driven by cost. Although there are pockets of excellence, there is a need for change and for collaboration and reform at all levels, including in the following six areas.

First, consumers must be recognized as experts in their own lives and be consulted in all decisions that affect their lives. Second, consumers and their families must be key players in all aspects of the mental health system. They should serve on boards of directors, assist in the hiring of staff, and be involved in review of policy and practice. We must aggressively move beyond the tokenism

that characterizes current involvement of families and consumers. Third, the research about what works and what doesn’t should guide the system and should guide funding decisions. This approach should include information about the outcomes of coerced treatment. Fourth, the medical model, which has a top-down hierarchy, must be replaced by newer models of care, which place the family and the person at the center of treatment. The chronic care model

championed by the Robert Wood Johnson Foundation is one of several good models to be considered. Fifth, no policy making or systems change should be undertaken without families and consumers as equal partners—from design to delivery. Finally, system design and delivery cannot continue to be based solely on cost containment or the ups and downs of the budget. Care must be based on a plan that evaluates cost, quality, and access.

Living Independently With Mental Illness

Dollie Hunt-Wilson

In March 1996 I was in my tenth year of employment as a licensed practical nurse at a psychiatric institute. Suddenly, without warning, I became obsessed with religion. Attending church and listening for “His” voice were my primary activities, and my ultimate goal was to consistently obey His commandments. After a five- to six-month period of total euphoria I plunged into what I refer to as the “dark side”—a state of constant doom and depression. This state of torment was so profound that it ultimately led to my first suicide attempt.

There are some ways that I could have been better helped when I first got sick. The first time I had my psychotic break I was paranoid and hearing voices that told me to hurt myself. I went to the emergency room at the local hospital. I was told to put on a hospital gown and was placed on a gurney, where I sat for 45 minutes by myself. During that time I got more paranoid and thought the nurses and doctors were talking about me. None of the staff came to tell me what was going on or how I could get help. I knew I needed help. After 45 minutes I got dressed and left the emergency room. I got my car and drove it into a utility pole. That was my first suicide attempt. The police at the scene of the accident got me connected to the emergency services of Crossroads Community Service Board, an outpatient mental health clinic. I may not have made that first attempt if the staff at the hospital had

known how to address my psychiatric needs.

I was admitted to a psychiatric unit, where I was eventually given a diagnosis of bipolar disorder. Upon discharge I was referred to Crossroads, where I was assigned to the attending psychiatrist and a case manager. Initially, I had frequent appointments with the case manager and the attending psychiatrist. As time passed and I was able to focus on reality, the appointments were spaced out. I returned to work after approximately three months and performed as expected for two years. I then began having mood swings, with depression being the dominant mode. I was readmitted to a psychiatric unit at a local hospital.

During this hospitalization I was introduced to electroconvulsive therapy, which I received for a five-week period. The treatments helped to alleviate the depression, but I experienced the side effects of memory difficulties. I now felt mentally as well as physically drained and knew that I could not return to my regular routine as I knew it, especially nursing. So I applied for and was granted disability retirement benefits. Over the course of several years, I was frequently in and out of the hospital for depression, with frequent changes in medication. Looking back, if I knew about the severity of the memory loss as a side effect of the electroconvulsive therapy, I don’t think I would have consented to it. Although the

doctor explained the procedure to me, I was not in the right frame of mind to make a decision about something like electroconvulsive therapy. I hope that health care professionals try to make sure that people with serious mental illness have the capacity to understand and to consent to a procedure like electroconvulsive therapy before they get it.

During this period of my life, my case manager was instrumental in helping me to be compliant with my medication regimen by providing pillboxes and suggestions to help me get into a routine of taking the medications. She was also instrumental in getting me admitted to a psychosocial rehabilitation program called Townhouse. This program was very beneficial for me. I was placed with peers who were also coping with mental illnesses. Progress did not take place immediately. However, during my attendance at this program I received guidance from my case manager, instructions through group activities, and routine medication management that allowed me to ultimately cope better with daily activities.

I also assisted with professional tasks at Townhouse, such as typing, answering the telephone, greeting visitors, and giving tours as well as

doing the daily billing procedures, which gave me a sense of worth. I also regained my self-esteem. I began to do all the Medicaid billing by myself. The staff at Townhouse helped me learn new skills and then allowed me the responsibility to use them. What has helped me a lot to stay healthy and learn to live with a mental illness independently has been the support of my peers and staff at Townhouse. I know I am in an environment where I will get the understanding I may need as well as have friends who are also coping with mental illness. I am proud that I am able to help others now.

Ten months ago I obtained a rewarding job as a psychosocial rehabilitation program assistant at another psychosocial rehabilitation program for older adults at Crossroads, and I thoroughly enjoy it. I continue to have medication reviews every three months, and I continue to have access to a case manager with whom I can confer when I do have difficulties, both of which are very reassuring. My doctor explains the medications and the side effects, and I look them up myself so I know what to expect. I have not had any psychiatric hospitalizations in two and a half years.

ence. Yet significantly more girls than boys met diagnostic criteria for posttraumatic stress disorder (PTSD)—almost 18 percent, compared with 11 percent for boys. More than half the study participants who had PTSD reported witnessing violence as the precipitating trauma. Another study of youths in California detention facilities found rates of current PTSD of 32 percent for males and 49 percent for females. These rates exceed those reported in community samples of youths and young adults, which range from 3 percent to 9 percent.

Other studies have found that the traumas experienced by delinquent girls were different from those experienced by delinquent boys. Boys were more likely than girls to report having witnessed a violent event, and girls were more likely to mention being victims of violence.

Traumatic stress may interfere with a youth's ability to benefit from the rehabilitative programs offered by the juvenile justice system and interact positively with others. For example, young people who have experienced trauma may have difficulty paying attention or controlling their emotions because of hypervigilance or hyperarousal. Traumatic memories of previous events may trigger angry or avoidant responses to staff members or other youths. Unfortunately, many correctional workers are not trained to provide the kinds of help needed by children who have trauma histories and emotional problems. They do not understand how past traumas may be affecting the conduct of the children in their care and may react punitively or in ways that are potentially traumatizing.

Traditional methods of preserving order and asserting authority in detention centers—especially tough, physically confrontational approaches—may backfire disastrously with children who have suffered trauma. A detention worker who resorts to “military” methods of control risks causing children with PTSD to reexperience the trauma—perhaps triggering a reaction that necessitates more physical contact, until the situation spirals out of control. The use of restraints with young people who

Trauma and the Juvenile Justice System

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Jenifer Wood, Ph.D.

Patient safety concerns extend to the undiagnosed and untreated youths in the juvenile justice system. Each year, hundreds of thousands of children and youths are put into a correctional facility of some type. Numerous studies conducted across the nation document high rates of mental and emotional disorders among these youths, including high rates of traumatic stress. Unfortunately, many juvenile justice facilities simply aren't equipped to care for young people who have special needs or trauma histories. From the perspective of these children and their families, the detention experience may even worsen their disorders.

The arrest and detention of a child can be a frightening and confusing time for the child and for his or her family. Some facilities are overcrowded, which increases the risk of injury and suicide attempts. Some facilities expose children in their care to new traumatic experiences or exacerbate memories of previous traumatic events.

In a recent study at the Cook County Juvenile Detention Center in Chicago, more than 92 percent of the youths had had at least one traumatic experience, such as witnessing violence or being threatened with a weapon. Significantly more boys than girls reported such an experi-

have been victims of abuse may be especially retraumatizing.

Studies have consistently found that among persons who are exposed to trauma, females are more likely than males to develop mental health problems. Girls in juvenile justice settings need to feel safe, and many characteristics of the detention environment—such as seclusion, loss of privacy, and insensitivity on the part of staff—can add to the negative feelings and loss of control girls feel. Some juvenile justice systems have recognized the need to adjust their programs and procedures to better meet the needs of children—especially girls—who have histories of trauma.

Recommendations for improving the juvenile justice environment for children with trauma histories include screening all children who

come into detention or correctional settings for PTSD and other psychiatric disorders and then providing access to evidence-based treatments and other clinical services. In addition, gender-specific programs for girls should be developed that focus on promoting safety, building nonabusive relationships, addressing victimization, and learning appropriate coping strategies. The involvement of families also needs to be increased. Families know their child best and can provide information that is critical to keeping the child stable and safe. Families can provide information about a child's developmental and educational history, the child's needs and strengths, the family's capacity to participate in treatment, the child's patterns of responding to people and events, and the child's treatment history. Finally,

correctional staff need to receive more clinical education and ongoing support, especially education about maximizing the use of nonconfrontational interventions and diminishing the use of seclusion and restraint.

Most incarcerated youths return to their families and communities. Protecting incarcerated youths from further harm while identifying and treating their clinical needs maximizes the chance of rehabilitation and successful reentry into society.

References

1. Whitaker R: *Mad in America: Bad Science, Bad Medicine, and the Enduring Mistreatment of the Mentally Ill*. New York, Perseus, 2003
2. Peele S: *Diseasing of America: How We Allowed Recovery Zealots and the Treatment Industry to Convince Us We Are Out of Control*. San Francisco, Jossey-Bass, 1999

Submissions Invited for Child & Adolescent Psychiatry Column

The editor of *Psychiatric Services'* Child & Adolescent Psychiatry column, Charles Huffine, M.D., invites papers focusing on systems of care for children and adolescents with serious and complex mental and behavioral disorders. In recent years great progress has been made in developing methods of addressing serious disorders in this population. In 2002 the journal began publishing a quarterly column in hopes of providing a forum for introducing some of these innovations to a broad mental health readership.

Dr. Huffine is soliciting reports of collaborative work on behalf of children's mental health among pediatric medical care systems, social service agencies, special education programs, the juvenile justice system, drug and alcohol treatment programs, and family advocacy groups. The column will feature papers that describe innovations in programming and new clinical methods to address the complex social and developmental problems of seriously emotionally disturbed children and adolescents. Papers should describe innovative clinical programs that are mindful of contextual issues, training that prepares psychiatrists to work in changing systems of care, clinical issues that arise in cross-agency collaborative work, and a broad range of related topics.

Papers should be no more than 1,600 words and should be submitted directly to Dr. Huffine. For more information about the new column or to propose a submission, please contact Dr. Huffine by e-mail (chuffine@u.washington.edu) or by mail (3123 Fairview Avenue East, Seattle, Washington 98102).

For general information on formatting, visit the journal's Web site at www.psychiatryonline.org. Click on the cover of the journal and scroll down to Information for Authors, which includes a section on columns.