Editorial

We Are Dying Out Here

Just get it done and quickly. We are dying out here." This powerful statement is one of hundreds the Depression and Bipolar Support Alliance (DBSA) received when we asked our constituency to review the executive summary of the President's New Freedom Commission on Mental Health.[1]

The DBSA, previously known as the National Depressive and Manic-Depressive Association, a patient-led advocacy organization assisting more than 3 million people each year, applauds the work of the President's New Freedom Commission. We are encouraged to see the Commission outline flaws in the mental health system and create a road map for action. DBSA's mission is to improve the lives of people living with mood disorders. Our organization shares the Commission's vision:

> We envision a future when everyone with a mental illness will recover, a future when mental illnesses can be prevented or cured, a future when mental illnesses are detected early, and a future when everyone with a mental illness at any stage of life has access to effective treatment and supports—essentials for living, working, learning, and participating fully in the community.[1]

The process was inclusive; the Commission was earnest in its efforts to reach out to people with mental illness, their families, patient advocates, and the general public. In addition, it employed communication systems accessible to people living with mental illnesses.

The bad news is that at their core, the Commission's findings vary little from the findings of President Jimmy Carter's Commission on Mental Health that described a broken patchwork of care over 25 years ago (Presidential Commission on Mental Health, 1978). Or for that matter, there's little variation from the messages delivered by the Surgeon General's reports issued in 1999[2] and 2001.[3]

As good and as thoughtful as the New Freedom Commission's recommendations are, the time has come to act. It is time to move beyond reports and address the public health crisis of an impaired system that people living with mental illnesses have to face every day. The time has come to put legs on the report and answer the desperate plea of millions of Americans to "Just get it done and quickly. We are dying out here."

We can take some actions as individuals—whether physician, family member, or patient—to make the changes suggested in the report a reality and to reorient our thinking from illness to wellness, from debilitating disease to recovery. DBSA focuses largely on empowering patients and their caregivers to take action today. To that end, DBSA is especially pleased that the Commission's second goal recognizes that "mental health care is consumer- and family-driven." Within this goal is a subgoal that underscores the critical role consumers and families have in orienting the mental health system toward recovery. One member of our constituency commented in response to the Commission's report:

> I was surprised that there was the emphasis on a recovery-based system for mental health. It simply makes so much sense. . . . Very definitely the emphasis should be given to the consumers to participate in the development of a national recovery initiative. In the past, my opinion has been slighted by the so-called experts—but thankfully not by my doctor.

The emphasis on recovery can be found throughout the Commission's report. That is good news for the patient. We need a system that includes some level of wellness and participation in life. Many of us want to be active, not passive partners in our own treatment. Even those of us most affected by these terrible illnesses can find ways to participate in our own recovery and the recovery of others.

We want to be engaged as peer-to-peer resources, supporters, teachers, motivators, and examples that these illnesses do not define who we are. After all, who knows the impact of these illnesses better than those of us who have been there? Most of us want our family and friends involved in our treatment and care. And most importantly, we want our treatment plan to move beyond symptom relief to a whole-person approach. The fact that the President's Commission embraced this issue is welcome news.

The bad news is that even a cursory glance at what it might take to move toward a rehabilitation/recovery model can be overwhelming. Several elements are necessary to achieve this goal:

- Patients who act as partners, who understand their illness, who ask good questions, who adhere to treatment, and who communicate effectively.
- Physicians who welcome a patient/physician partnership, who communicate well, who have the time to communicate, and who can be reimbursed for services beyond medical management.
- Treatment plans that expand beyond medication management, that move into a "whole person" approach, and that move beyond symptom relief—movement from illness to an individual's unique concept of wellness. This concept may include a home, a friend, meaningful work, the ability to leave the house, and/or a cessation of alcohol or drug abuse.
- Health care staff that can support systems from a partnership perspective and not from a command and control perspective.
- Funding for programs that facilitate all of the above.

With all that must be done, dismissing the report as idealistic, unrealistic, simplistic, or unworkable can be a dangerously easy step. Too many will see the report as something for government entities and insurance companies to struggle with. Yet, health care providers and patients can address each of the 6 goals and 19 recommendations outlined in the report. Here are 5 achievable tasks DBSA believes all patients, family members, and health care providers can and must do to reposition mental health care as patient- and family-driven.

1. Communicate More Effectively

> "I find that many helping therapists and psychiatrists have a very hard time working with me—they just are not used to a partnership."
>
> —DBSA constituent responding to Commission report

Working as equals as partners in health and seeking to solve a problem more often than not must include new behaviors for patients and physicians alike. The entrenched concept of "physician as oracle" must be shaken. It is still a commonly held belief that all health care workers are sufficiently knowledgeable about all mental illnesses, skilled in diagnosis, and familiar with the latest research and clinical practices as well as the full range of available treatments.

Finally, face-to-face time with a physician is often so limited that there is no opportunity to have our concerns, fears, and questions addressed. When health care providers speak to us, they often do so in "physicianspeak" (the mysterious language physicians are taught during training). Speaking to patients and their family members in a way they cannot understand can be frightening and is of no benefit.

Physicians are often surprised to learn that they are not communicating effectively. A recent DBSA survey[4] showed that 63% of patients left their appointments feeling that their primary care physicians did not explain their illness to their satisfaction, and 57% felt the same lack of communication regarding their treatment. Another survey[5] of primary care doctors and patients revealed that doctors believe they tell their patients about side effects 69% of the time, but just 16% of patients report hearing information about side effects. Yet another survey[6] revealed that 84% of us want to be given educational materials, preferably not published by a pharmaceutical company, yet only half are given any easy-to-understand, medically accurate materials.

When DBSA constituents were asked, "When you go to your physician to be treated for your depression or bipolar disorder, what one thing would you like to see changed?" the number one response was "Spend more time with me; don't rush through my appointment."[7] We believe there are many ways that the issue of time constraint can be addressed: e-mail (patients' number 1 choice), journaling, trained office staff, and referral to a DBSA peer-run support group.

Doctors and patients must develop a mutually effective way to communicate to ensure they are working in partnership. DBSA has created a variety of tools to help patients improve communication with their physicians. These tools also stress to patients the importance of assuming responsibility for their wellness as equal partners with their health care teams.

2. Set and Work on Wellness Goals

> "Many of us get sold on the message we are disabled, crazy, lunatic losers and need this report to remind us we are not. This is the heart of the stigma issue, and the motivational reeducation needed of consumers, the professionals who treat us, our families who worry about and may not understand us, and the community and nation at large."
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> —DBSA constituent responding to Commission report

> "I also think it is important to recognize that many, many people will never 'recover' to the point where they can go back to life as it may have been, but they can build a life which is meaningful at the stage of recovery they are capable of accomplishing."
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> —DBSA constituent responding to Commission report

A recent DBSA survey[8] revealed that the majority of patients (80%) were having conversations with their health care providers about more than just medication, which is very impressive and welcome. However, DBSA was concerned to see that most patients (63%) were not setting wellness goals. DBSA believes that setting and working toward achievable goals is at the core of achieving wellness. Physicians should include a discussion about wellness goals every time they meet with a patient. The physician and the patient must mutually accept these goals. DBSA believes a person cannot know if they are as well as they can be if there is no goal to reach.

According to surveys of our peers, in addition to symptom management, patients are most worried about (1) finding/keeping intimate relationships, (2) adding more friends to our lives, and (3) finding/maintaining meaningful work. Wellness tools frequently used by our members, in addition to medication management, include (in order of utilization): peer support groups, some kind of music, healthy diet, exercise/walking, pet therapy, journaling, writing/poetry, meditation, and some kind of art/craft. These tools can form the foundation for effective wellness goals set by physician and patient. Or as one constituent said:

> "Treating mental illness in a person requires looking at a whole person—community, physical, spiritual, medical, employment, home life, etc. Find out what is in the best interest for individuals affected, their families, and full recovery by offering options for full participation in all decisions."

3. Involve Family/Friends

> "Recovery, in large part, is an issue of motivation, family and community support, adjustment to medical issues, medication balance as well as compliance, and a change in the system from hiding us in a group home, or on the street, or in a hospital and treating us like zombies to treating us like people who have a problem and need some help. We have aspirations, many of us are bored, would like to work, are stuck by the stigma of our illness, the worries of our employers, our own fears in discussing our illness with employers, family, community people, as well as the strictures of SSI [supplemental security income] on income limits."
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> —DBSA constituent responding to Commission report

> "More than medications, we need to know that we are not alone."
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> —DBSA constituent responding to Commission report

At DBSA, we often say that mental illness is not considered "casserole worthy." If a mother goes to the hospital because of her breast cancer, the neighbors are over with casseroles within a day. When we are hospitalized or take time off to cope with a downswing, people stay away, primarily because of fear, ignorance, and stigma. Mental illnesses are diseases of isolation, and we can become even more isolated at a time when support is critical. Family and friends do not know how to support us. Most of us do not dare tell our employers. No one brings casseroles when we are ill.

The majority of us (65%) want family and friend involvement in our treatment management, but this is not encouraged or made possible by the majority of our doctors (62%).[7] We need your help to involve our families and friends. They need to know how to support us so that we are less frightened, not so isolated, and more likely to adhere to our treatment plans. DBSA has many tools to enable the family to get involved, such as the *Helping a Friend or Family Member* brochure and worksheets, our *Mood Calendars* and our *Wellness Kit* that the family can use in concert with loved ones, our *Hospitalization* brochure that can be used to prepare for or cope with hospitalization, and a book, *Storm in My Brain*, illustrated by and written for children, with tips for teachers and parents. These and other resources are available online at www.dbsalliance.org/store/index. We encourage physicians to provide these materials to their patients.

4. Investigate and Partner With Recovery Programs

> "The report contains good information, somewhat common sense. However, there appears to be little structure regarding implementation. Making a wider selection of services available to the public using Medicaid funding has the potential to be slow and bureaucratic. I believe the most valuable resource lies within the partnership between consumers and the health care community, not policy makers."
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> —DBSA constituent responding to Commission report

States are beginning to implement peer-to-peer–based recovery programs. A model developed in Georgia and expanding throughout the United States has patients serving as peer specialists, assisting with case management and delivery of services to other patients, all reimbursable through Medicaid. Physicians, family members, and patients wanting to know if this program is available in their state can contact a local member of the National Association of Consumer/Survivor Mental Health Administrators (www.peersupport.org). Utilization of and demand for this kind of service can help reposition mental heath care as patient- and family-driven. In addition, forming partnerships between physician and patient groups such as state chapters of the American Psychiatric Association, American Medical Association, DBSA, and the National Alliance for the Mentally Ill to drive changes in care is also an effective tool to reposition services.

5. Use Our Collective Voice to Push Funding Programs and Insurance Parity

> "Long term funding is very important. Recovery takes time, and grants and monies that dry up after 2 or 3 years, closing programs, aggravate the problem, causing distrust and

> many times stall recovery for consumers who must depend on an unstable and inconsistent mental health system."
>
> —DBSA constituent responding to Commission report

> "I am scared to death that housing subsidies, economic subsidies, and any kind of help at all is drying up from federal and other funding streams, and those of us who are mentally ill will be left behind with a mop and a broom in hand or worse yet be herded back into large filthy institutions."
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> —DBSA constituent responding to Commission report

> "I do feel that no one understands the financial part of being mentally ill. I stand to lose everything my husband and I have worked for due to this illness. . . . I don't know what I am going to do. I can no longer see anyone because I simply cannot afford to."
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> —DBSA constituent responding to Commission report

It is a disgrace that after all this time, we have not achieved mental health insurance parity. That insurance companies are still allowed to reimburse "real" illnesses at a higher level than "mental" illnesses is a travesty. Can you imagine not being reimbursed for heart disease treatment? No, but the vast majority of the millions with a mood disorder must live with the risk of being the 1 in 5 who takes his or her own life. We each need to intensify our push for parity. The best way we can do this is to form coalitions to dramatically increase the voice we need to get parity passed. This hasn't happened, so in this way, we are our own worst enemies.

In addition to parity, we need to continue to push for expansion of programs and services to provide long-term solutions for those living with mental illness. We each must continue to contact our legislators and to cast our vote come election time on these issues. Nothing will change until and unless we raise our collective voices about these issues.

We have presented 5 simple things we each—physician and patient alike—can do to begin to implement the findings of the President's Commission. These tasks are not the total answer, they are just a start, and to some, they will seem too modest an effort.

Those of us in the mental health advocacy community retain our strength and focus by remembering that "the longest journey begins with one step." If each of us, patient and physician alike, starts somewhere, we will eventually have an answer when faced with the comment, "Just get it done and quickly. We are dying out here."

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Editor's Note: The Depression and Bipolar Support Alliance (DBSA) is a nonprofit patient-directed organization dedicated to the understanding and treatment of these illnesses. As a support and advocacy group, the DBSA provides educational materials to the public, peer-led support groups, and public policy initiatives.