Disclosure of one’s own experiences with psychiatric disability can be both exhilarating and depressing. This article shares experiences of the author and others in their disclosure, and provides some ideas about the risks and benefits of disclosure.

Secrets and surprises are often the leavening of life. They can add joy and mystery and interest in a family as birthday parties are planned, or presents are made or purchased for holiday giving. However, when the secret feels extremely uncomfortable, it can eat into one’s heart and soul, and can affect relationships and work. Such is the secret I held from my friends, family, and colleagues as I hid my psychiatric hospitalization, the Electro Convulsive “Treatment” (ECT) received while there, and my continuing experiences with depression. My husband, my son (who was 10 years old at the time of my hospitalization), and my mother were my support group during this terrible time.

The purpose of this article is to explore the dynamics of disclosure—both positive and negative aspects—by examining my own and others’ descriptions and reasons for disclosure. Sometimes disclosure is a choice—when one has built a new life beyond the experience of psychiatric disability. Other times it becomes a necessity when a new episode arrives or something is needed to be able to continue a productive life. Some never get the chance to make the choice, for they live with the presence of the illness every day. We will explore both the disclosure decision and when and how to make it as well as thinking about what can happen after disclosure.

The dynamics of disclosure are many and varied. On the negative side, there is the fear of discrimination and stigma, including its impact on your employment, and grief about lost time and opportunities. The positive side includes the recognition and acceptance of supports that were always there, the building of new relationships, the beginning and continuation of the healing process, learning about healing, recovery and well-being, and sharing your new perspectives with others.

Disclosure Decision Process
There comes a time when a decision must be made about disclosing this painful secret in your life, and the continuing problems you can and do face. This may be a job change, another episode of psychiatric illness, or a change in location of your home. You may need to have some accommoda-
tion in your working conditions to assist in the maintenance of your mental health, and in your productivity. You may have had some new experiences that encouraged such a decision. Or, you may find new resources, internal or external, which can affect your decision. The supports you have in your life, your comfort with and control of your psychiatric disability (e.g. where you are in your recovery), your willingness to explore, reach out, and touch a new aspect of life, and your level of fortitude, will determine when or whether you will disclose your psychiatric disability to friends, family, colleagues, and the world in general. An episode that requires treatment may force disclosure to colleagues and friends. Conversely, the discrimination and stigma you see and feel, inappropriate and demeaning language, or the threat or fear of losing your job may lead you to decide not to disclose.

Barriers to Disclosure

Secrecy and control. When one begins to think about disclosing your struggle with psychiatric disability, the reasons for continuing secrecy battle with the desire to “get it out into the open.” You begin thinking “I don’t want to think about the time(s) when my life was out of control!” You want to leave the bad times behind, and not bring them up to the light of remembrance. Your life is out of control when you are so depressed that the world appears dark and unfriendly, and you cannot participate because you are afraid. Your life is out of control when your psychiatric illness takes hold of you, and you are confused and need the help of a strong, friendly hand to guide you back to the light. These are very difficult times to remember—and sometimes “treatments” block the memories and you do not know if you are better, since you cannot remember when you were ill. It may be that the illness, the “treatment” and the cause are too difficult to remember. In interviews of survivors of trauma, Ann Jennings found the reaction to questions about seclusion and restraint in hospital treatment were feelings of rage and anger, and the message was, “I can’t talk about it!” (Jennings, personal communication, 1996).

Shame. Because mental illness has a history of being “hidden” and “shameful,” you might carry that shame with you. Pat Rangel, in her testimony in People Say I’m Crazy (Campbell, ed. 1989) says, “Once I crossed that line and had to be hospitalized, I felt very ashamed and like I wasn’t like everyone else. I didn’t want anyone to know” (p. 43).

This “line” that we cross into psychiatric illness makes us feel degraded, hopeless, and lost. Dan Fisher (a consumer1 psychiatrist) said, “It took me a long time to regain my self-esteem. I almost did have to become a psychiatrist to regain my self-esteem—to prove to myself, to prove to the world, to overcome the labels. Once they’ve done that diagnosis, you just can’t get rid of it, from your records and your heart” (Reidy, 1994, p. 7).

Discrimination and stigma. A very real issue in the decision to disclose is discrimination, sometimes referred to as stigma. Discrimination is defined as acting on the basis of prejudice. A definition of stigma is a brand, or a mark of infamy (Webster’s II New Riverside University Dictionary, 1984). Erving Goffman, in his landmark volume, Stigma: Notes on the Management of Spoiled Identity (1963), defined stigma as “an attribute that is deeply discrediting” (quoted in Reidy, 1994, p. 3).

Stigma is best epitomized for consumers of mental health services by both the title and the content of a paper written by Deborah Reidy (1993) “Stigma is Social Death.” Reidy interviewed forty-six people, thirty-four of whom were current or former consumers of mental health services. “The stories told by these consumer/survivors tell of painful experiences of exclusion, rejection, and discrimination, often through hundreds of subtle day-to-day interactions” (Reidy, 1994, p. 3). It is these “subtle day-to-day interactions” which are most feared by people who have not disclosed their own psychiatric illness, but have listened to and watched those who have. It is the difference between being viewed as a competent, productive, and an accepted person, or being viewed with disbelief in your ability to do a task or complete a job.

Discrimination and stigma in the mental health system. Tragically, consumers interviewed by Reidy (1993, 1994) indicated that the greatest amount of discrimination and stigma they encountered was in the mental health system itself. Issues most often mentioned were the power and control imposed by providers, being treated as having lower status than staff, regimented and dehumanizing practices, separation from the community, disbelief that people with psychiatric disabilities can grow and learn, lack of respect for privacy, and inadequate access to information.

Brooks (1995) makes a similar observation: “What is no longer remarkable to me is that the most dehumanizing and stigmatizing interactions have been within the professional community of mental health treatment and research” (p. 1013). She describes this experience:

Any pretense I may have had about being treated with civility (by mental health staff) was symbolically stripped from me one morning in 1974, after having spent a night

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1 People with mental illness prefer being called by their name first. We use consumer in this paper to depict people who are sad, who experience mood swings, who see or hear things that others do not see or hear, or have experienced terrible trauma.
Locked in a seclusion room, for reasons I cannot remember. After many hours in the seclusion room, hallucinating and sleeping, I had pounded on the door, screaming that I had to go to the bathroom. No one ever came, so in total humiliation, I urinated on the floor in the corner. By refusing my very basic request, implicit in normal social mores, the staff “baptized” me as a patient in my own urine. It took me ten years after that event to even begin to confront and analyze that experience, and only recently did I finally accept, despite nearly 20 years without problems from the illness itself, that the stigmata are permanent. (p. 1014)

Once you disclose your involvement with the mental health system as a recipient of services to employers, colleagues, friends, or mental health workers you may never be seen again as a “complete” person. This is particularly true in the mental health system. Brooks (1995) again comments: “The existence of my medical history, now more than 20 years old, simply overwhelms all of the accumulated evidence of my professional life preceding the illness and the nearly two decades of accomplishments since then.” (p. 1014)

Discrimination and stigma in the workplace. Accommodations requested in the workplace have been denied, or have been inadequate. Both Monson (1995) and Carringer (1995) describe highly productive jobs, which were impacted by their episodes of illness, resulting in absences from the work site. In their struggle to keep their jobs, they worked overtime, which sometimes resulted in further episodes of illness. The most difficult thing to face was the attitude of co-workers and management, who could not or would not understand, and who put limits and expectations on the work to be done, which would inevitably lead to failure.

Even the Americans with Disabilities Act, which is supposed to protect people with disabilities and provide reasonable accommodation in the workplace, is not a panacea, especially for people with psychiatric disabilities. For psychiatric illness is a “non-apparent” disability—until it interferes with the completion of work assigned. And with this comes the dilemma of whether to disclose or not, which is described in an editorial in The Journal of the California Alliance for the Mentally Ill (1995).

The dilemma is essentially a problem of uncertainty. The worker with a non-apparent disability must make a choice without knowing, in advance, how the employer will respond to disclosure, how far the information will spread in the workplace, or in what ways it might impact on his or her personal or professional “quality of life” over time. (p. 4)

When a person discloses their experience with psychiatric illness during a job application and indicates a need for reasonable accommodation, the prejudice of employers about psychiatric illness can affect his/her chance of getting the job. The attitudes of co-employees in the workplace may also be affected. This discrimination/stigma is even supported, in a way, by the ADA itself, with provisions that allow employers to abridge the rights of people with psychiatric disabilities. Campbell (1994) points out:

... there is the direct threat exclusion, which exempts employers from the requirement to provide reasonable accommodation to a person with disabilities if that person poses a significant risk to the safety of others. ... Due to widespread acceptance of the cultural stereotype of the violent mental patient, the ADA inevitably subsumes issues of psychiatric stigma and discrimination. When the attitudes of employers towards hiring individuals with disabilities are examined, the absence of accommodations for persons with psychiatric disabilities appears to be a function of stigma rather than of difficulties associated with developing workplace accommodations or the cost of such accommodations. (p. 134)

Why Disclose?
With these bleak pictures, we might ask the question “Why disclose?” If your psychiatric illness is under control, and you can perform the tasks in your daily life without disclosure, this can be a very difficult question, and can only be answered by the person contemplating disclosure. One reason might be to obtain “reasonable accommodation” in the workplace, which is available through the Americans with Disabilities Act (ADA), but only if you do disclose. With this “invisible disability” (until it shows up in symptoms or absences from work) it is difficult to educate employers that accommodations are needed, and what they should be.

Some people have found acceptance in the workplace, and understanding during difficult times. LaPolla (1995) describes the reaction of concern and compassion from the California State Senator for whom she worked, who gave her a leave to attend to her immediate psychiatric needs and then rearranged her schedule when she returned to work. She comments: “Reasonable accommodation saved me from abysmal failure” (p. 54). She describes the stages of acceptance of her own illness and then her need and desire to disclose. There needs to be a readiness, a compelling feeling that it is the right thing to do.

As the pieces of my former self slowly emerged, I grappled with the issue of disclosure. If I truly accepted my illness, why was I still afraid to tell? I survived the abyss; now, I needed to survive society’s stigma. Something in me wanted to tell. A deep desire to dispel the myths of
mental illness, the myths I lived with all my life, raged within me. (p. 54)

She began her disclosure quietly with some coworkers. Then it became easier, and she disclosed at a legislative breakfast where she was representing the Senator. A newspaper columnist asked for an interview during National Mental Health Month. Her disclosure continued with the writing of the article for publication.

Callner (1995) speaks of the positive environment he has found in the workplace because of his disclosure of his Obsessive Compulsive Disorder (OCD):

A very significant and “life-changing” situation has occurred during my post-breakdown teaching years. The more I have spoken out about my OCD to college students and to the community, the more they have “expressed” their same or similar problems. It is almost as if I gave them permission to express their pent up emotional issues. It is simply amazing to me. Just by being open, honest and direct, my students and the general college community have given me more respect, admiration and love than I could have ever imagined. (p. 33)

In discussions with colleagues who have disclosed, and are happy (or at least content) with their disclosure, and in reading disclosure statements such as those mentioned here, there seem to be some common areas. First, the environment is “right.” Colleagues, supervisors and/or family are or appear to be open and willing to listen and accept. There is a positive political environment, where asking “consumers” for their “input” is the politically correct thing to do and consumers are recognized as having valuable information because of having been an “insider,” i.e. a user of mental health services, or a person who has experienced psychiatric illness. Second, you, the discloser, must be ready. Disclosure needs a great deal of thought and preparation through discussions and practice with “what if” situations with those who know about your psychiatric disability. You don’t disclose in a vacuum. It is not the subject for conversation at a party. There is generally some “reason” for disclosing which feels compelling. This reason may be immediate, such as a job advertisement for a “consumer.” This reason may be longer term. It may be a discomfort with yourself and your secret. There is a need to be at peace with the conflict of this “secret.” You may recognize that you have distanced yourself from those whose psychiatric disability is more severe or in need of more treatment, and you want to lessen that “gap.”

Generally, people who have disclosed without the pressure of an episode of illness have thought about it for some time, and then began slowly. In the long run, the people with whom I have discussed disclosure, revealed in both words and actions that at the heart of their disclosure was the desire to help someone else, to do something which would improve and impact the mental health system, to make the world a better place for those who were not so fortunate, and in the end, make it better for themselves.

Jean Campbell applied for the job as Director of the Well-Being Project, and to do so, she applied as a person who had experienced psychiatric illness. In the Introduction to her dissertation, she discusses her own disclosure:

To search for truth appears to be part of an open dialogue that begins with the courage to risk the comforts of an unexamined conscience. ... It is only after confronting my own vulnerability that I realized that the struggle to affirm people’s humanity is a proactive stance towards living one’s own life every day. It is also the juice of possibility. (Campbell, 1991, p. 1)

My disclosure decision. For me, it was a slow dawning. Although I had worked in evaluation and research in mental health centers for some years, I had been in the administrative section, and generally removed from daily contact with people who used the mental health services. Then we moved to Maine. Because we were renovating our summer cottage for year-round living, I housed my computer at my husband’s office—where he was director of a rehabilitative social club and vocational program. His door was always open to all who wanted to talk. Thus, I became, literally, the “mouse in the corner” who could listen without intruding. It was a revealing education for me to see people who struggled daily with their psychiatric disability, and yet who were so open and friendly and accepting. In terms of their debilitating experiences, my feeling was “There but for the grace of God, go I.” But in terms of their openness to discuss their problems and joys with each other, to open their hearts to others, and to enjoy life as they could, my feelings were “Why can’t I . . . ?”

Your disclosure decision. Once you have begun disclosing—then what? How far do you go? To whom do you disclose—or not disclose? This is still a personal decision, and may be the result of the reactions you get as you disclose. When I disclosed to a former colleague, she said sarcastically “Oh yeah? And so are we all! (psychiatrically disabled).” If I had many of these kinds of reactions, I may not have gone any further. However, for the most part, friends and colleagues were understanding, even appreciative, and praised me for my “courage.” Also, some revealed to me their own struggles. And then I began to be “connected” to other consumers, who shared their lives and caring with me and for me. I knew that what I had done was right, despite the struggles I might face. Fisher (1995) recommends
that you be very prudent in regard to disclosure.

How much, in what form, to whom, when, why and in what location one discloses are all important parts of the decision. … In fact, disclosure is only a problem to the extent that there is discrimination. … You have to pick someone you can trust, someone who is tolerant, understanding and fearless about the experiences. More often this will be a peer—one who has gone through a similar experience and is also in the process of recovery. I’ve found it valuable to reexamine experiences with a trusted peer and try to discuss thoughts and feelings about past episodes and the treatment you received. By exploring your own understanding and objectivity you also begin to develop a strategy for further disclosure. (p. 55)

**Benefits of Disclosure**

And what are the benefits of disclosure? A number of the people who have shared their disclosure statements also comment on this. Callner (1995) suggests that disclosure is therapeutic, and can lead to greater emotional wellness.

The true depression of keeping my turmoil a secret is that it creates more turmoil, more isolation, more fear. … What I am suggesting is that letting those secrets out in a safe environment, with nurturing people, is in fact a treatment modality for emotional wellness. … I believe that the suppression of expression is what makes us ill. … My suggestion to those still in secrecy and isolation with their emotional issues due to fear is this: prudence, restraint and safety are a prerequisite to letting out a secret for anyone, but with that in heart and mind, take the risk to “let go” of your secrets—it is the pathway to wellness—in the workplace and elsewhere. (pp. 33-34)

LaPolla (1995) comments on her feelings of peace and freedom from her disclosure:

Disclosing my manic depressive illness was freeing. I am at peace with myself. I have not suffered because of my disclosure; I may in the future—telling is risky business. My story is a success story. Others are not so fortunate. Society needs to be enlightened about mental illness. Stories need to be told. I will tell mine. (p. 54)

And, at the end of her dissertation Introduction, Campbell (1991) describes the results of both the disclosure and working with others who have experienced psychiatric illness.

Perhaps there is a necessity to this process that allows a person to be estranged in the discovery of truths, to be able to communicate, share and experiment without compassion. … Still, when you stand next to someone and begin to speak, you want to say I am here, I feel, I am part of the joy and pain of the moment, not as spectator, but as another being. In this telling comes a respect for yourself and others and an obligation to be responsible for what you say and feel. There is also the recognition that true understanding requires conscience and the courage to feel another’s joys and pains because they are also ours. (p. 6)

For me, there have been multiple benefits, and they continue to expand. I share the therapeutic feelings and the sense of freedom which disclosure has given me. But much more than that, it has provided me with friends who are also supportive colleagues—friends who care what happens to me, who rejoice in my joy and weep with me in my sorrow. I have also found support in sharing my “coming out” story with family, colleagues and friends. My brother, a minister, now sometimes asks me about possible approaches to people with mental health problems, even though he has extensive training in pastoral counseling. My minister thanked me and indicated he would have a clearer vision and understanding, after having seen psychiatric illness through my eyes. My colleagues at work, with whom I share responsibilities for mental health research and evaluation, look to me for the “consumer connection”—in developing interview questionnaires, in editing for sensitivity to language, and in research design to address issues of importance to consumers. Also, I have found a “mission”—to educate non-consumer colleagues, acquaintances, and contacts. And each time I do this, it invigorates me and readies me to speak more clearly, and to be more comfortable in letting people know when and how they offend, and how they can improve.

And it works! I would like to share two examples. I was a member of a committee to review the evaluation plans for a national homeless study. The psychiatrist in charge of the data collection was describing how they would contact homeless persons and that at first contact, they would in their notes describe the person. His words were: “We can note what they look like—even whales can be identified by different markings!” I told him I was NOT a whale, and that his language offended me. He immediately apologized. But a few years later, he met a colleague of mine at a conference, and he commented on my “dressing him down.” He also said “But she was right, you know!”

In a federal grant review committee in which I was a member, the Guide for Applications required that service recipients be involved in the design and evaluation of the project. It was clear that most of the applications had not involved consumers in the design of the project, and that they did not know how to include consumers. In addition to the thorough examination and critique of the five applications that were assigned to me, I began commenting on both this area and the area of risk to human sub-
jests, which also was generally handled badly. I developed a standard statement that said, “Risks and benefits are to individuals involved in the study, NOT to the system, nor to the agency. It is a risk to share information about yourself with interviewers who are paid by the mental health system.” This became known as the “Ruth Factor.” I had to leave before all the reviews were completed, but I was told later that they included the “Ruth Factor” in all their deliberations. These are successes which send me on to do this again, and perhaps, the next time that group of people, or that psychiatrist deals with concepts which affect the lives of persons with psychiatric disabilities, they will remember, and they will act differently.

Support for Disclosure
During this discussion about disclosure, little has been said about the type and amount of support needed to be able to recover, and to disclose. There have been some allusions to this topic by authors already mentioned. LaPolla talked about the understanding and compassionate State Senator she works for. Callner mentions the support he receives from his students and colleagues in the college where he teaches, and Campbell expresses the support of standing next to someone and sharing the joy and pain of the moment.

My support began long before my psychiatric hospitalization, but it became very evident during this time. My mother, who lived 1200 miles away, sent me a card with a note in it every day. My husband came to the hospital every day. And when I could go out on a pass, my 10-year-old son also came to be with me, to go to the park, to go bowling, and to put his arms around me. He comforted me—when I could not comfort him. There have always been calls between our family members—in good times and bad. When my mother was dying in 1991, I was able to send her cards and notes, and call her on a regular basis. This is part of my own recovery and supports me in my disclosure.

In addition, I have gained support from other consumers—those whom I met in the first months of my disclosure, who heard my fears, talked me through my tears, and believed that I could make a contribution. This support continues through phone calls, e-mails, visits, cards, and “knowing someone is there who cares.” Support comes also when I am asked to speak or submit a paper for a conference. Generally the support comes from consumers—some of whom I know, and others I may not have met. At every conference, we tend to converge to talk, have fun together, and to “be there” when needed.

However, support has also come from colleagues with whom I work on a daily basis. They value me for myself first, and then they value my “consumer perspective” and my goal of training consumer researchers.

The lack of social/family support can have a negative effect. Monson (1995) describes a number of devastating family experiences which exacerbated her mental health concerns, and often led to psychiatric hospitalizations as well as causing absences from and affecting her work:

… in 1986 a miscarriage, ... in 1987 another miscarriage—this time would have been triplets ... in 1988 my husband and I separated. My father was diagnosed with chronic leukemia ... ’89 brought divorce. Then, in 1991, my best friend—the person I was closest to, my mother, died after a year’s illness. (p. 48)

Support from people in the mental health profession. People who work in the mental health system can make a tremendous difference in the lives of the people they touch. As they listen to disclosures made to them every day, they can listen to show they believe what is being told, they can provide hope, and they can treat people who have psychiatric disabilities with respect and dignity. And by so doing, they can help to begin the healing process—which may then grow and become a statement of disclosure to help others.

SUMMARY
The decision to “come out” for those who have not declared their “consumership” is a personal one, and depends upon many things. It may depend upon where you are in your recovery, and how comfortable you are with even the thought of recurrence of the illness. You
may feel compelled to share your “secret” to be freed from the feeling of always having to hide your illness. It may also depend upon the environment of acceptance and understanding in which you live and work. This environment includes family, friends and colleagues, as well as the public policy attitude and atmosphere about mental health. You may need to have some assistance or “accommodation” to be able to continue to work while you live through some difficult times. Accommodations might include shorter hours, flexible work time, released time for therapy visits, planning of your work load so that you can better plan your tasks and time, or training in areas where you are expected to produce, but your skills need to be upgraded. If disclosure is not forced upon you through an episode of illness, it should be approached with careful thought and preparation, “trying it out” on close friends or peers, and discussing your reactions with people who understand and support you.

For those who do decide to disclose, the opportunities are many. You may simply want to revel in the freedom of living without this secret. It may be that you help someone understand a better way to talk about mental health and persons with psychiatric disabilities. It may be as a “consumer representative” on an agency board or on a committee. You may want to tell your story through narrative, poetry, or art. The people quoted in this chapter have written and published their stories. There are also books and articles written by people with mental illness to read and share, such as On Our Own (Chamberlin 1977), Sing No Sad Songs (Balter & Katz, 1987), or Cry of the Invisible (Susko, 1991). You may be called upon to speak, or to be a part of a panel at a conference. It is becoming “politically correct” to include consumer perspective in mental health program planning and research. We, who have used or are using mental health services, must continue to insist that we be recognized for our EXPER-TISE—in service provision, in research, in program planning, in statistical methods, or other skills, as well as for our EXPERIENCE as recipients of mental health services. You may be able to challenge the discrimination/stigma of those who do not know and understand the abilities and training of consumers. This may include requesting the implementation of the ADA in your work situation. Moore (1995) indicates that in order for the ADA to become effective for people with psychiatric disabilities, there must be more disclosure and testing of the accommodations.

Although the ADA clearly provides a legal mechanism to combat discrimination, its ability to impact the stigma of mental illness and the fear and prejudices of society is uncertain. Without the law we have nothing. In order for the law to work for people with mental illness, it will take the courage of many of us to come forth and disclose our disabilities and request the accommodations we need in order to function in the work force at our greatest capacity. Not until society sees who we are, what we can do, how many of us there are, and throws away the stereotypes and generalizations, will the rights provided by the ADA be realized for people with mental illness. (Moore, 1995, p. 26)

The benefits of disclosure cannot be described more clearly than in the statements already quoted in this paper: “...take the risk to ‘let go’ of your secrets—it is the pathway to wellness—in the workplace and elsewhere. What a wonderful sense of being alive if elsewhere can be everywhere” (Callner, 1995, p. 34). “Society needs to be enlightened about mental illness. Stories need to be told. I will tell mine” (LaPolla, 1995, p. 54).

As we speak out in our various ways, we educate our family members, people who work in the mental health system, researchers, legislators, and others to be more aware of the ways they can enhance the recovery and freedom of persons with psychiatric disabilities. They need to recognize both the courage and struggle in speaking out about our experiences. And they need to join us in the movement to change the mental health system to one where each person recognizes the value and worth of every other person—and that every person is given the opportunity and encouragement to recover.

REFERENCES


