

**"Stigma is Social Death":
Mental Health Consumers/Survivors Talk About
Stigma In Their Lives**

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Executive Summary

Forty-six people were interviewed to determine their views on the topic of stigmatizing aspects of mental health programs. Of the forty-six, thirty-four identified themselves as current or former consumers/survivors. Some of these individuals were also mental health practitioners or professional advocates. Ten participants were family members or professionals who did not identify themselves as consumers/survivors.

People described a number of sources of stigma. Major sources included family, friends and intimates, the job market and co-workers, neighbors, people at church and in school. They also described the practices of the housing market, insurance companies and the social security system as being stigmatizing.

While respondents cited a variety of sources of stigma, most frequently mentioned were the attitudes and practices of the mental health system and its workforce. Following are attitudes, beliefs and practices within the mental health system thought to be stigmatizing.

Issues relating to **power and control** were most often mentioned. These included the practice of forced treatment as well as threats of forced treatment or of no treatment. People also cited lack of involvement in treatment planning or other aspects decision-making about their lives. In addition, restrictions on the freedom to come and go, being "placed" in a house or apartment, and other examples were given.

The experience of having **lower status than staff** within the mental health system was commonly mentioned. Many examples were given, including cues within the physical environment such as separate staff-client bathrooms and eating areas, demeaning and infantilizing interactions between staff and consumers/survivors, differences in status embedded in program policies, and discriminatory treatment in employment of people with psychiatric disabilities as mental health workers.

Regimented and deindividualizing practices of both institutional and community programs were described as stigmatizing. Specifically, respondents

mentioned dehumanizing admitting procedures, regimented activities, having to wait for appointments, and being forced to accept the psychiatric label.

A number of respondents described the practice of **separating people with psychiatric disabilities from ordinary community life** as stigmatizing. Several people also commented on the practice of grouping people with similar labels.

The absence of challenge or orientation to growth within the mental health system was also commonly described as stigmatizing.

The **lack of respect for privacy** was seen by a number of respondents as stigmatizing. Combined with the experience of always being observed by staff was the sense that one's behavior was "overinterpreted" -- in other words, that any normal feelings or behavior were interpreted as pathology or symptoms of one's illness.

Some respondents indicated that they felt **inadequate access to information** was stigmatizing, both to people with psychiatric disabilities and their families.

Other stigmatizing attitudes, beliefs and practices included: Lack of attention to potentially stigmatizing personal characteristics such as effects of medication and personal appearance; stigmatizing language; "second hand services"; and cues in the physical environment from the asylum era such as locked cabinets, bars on windows, etc.

Respondents then described the effects of these stigmatizing attitudes, beliefs and practices. Their comments focused especially upon "internalized stigma" and its consequent effects on behavior and self-esteem: low motivation, anger, depression, heightened sense of vulnerability, social isolation, and stifling of growth and productivity.

Participants had many suggestions about responding to experiences of stigma. Some of the suggestions focused on strategies which might be employed by the stigmatized person him or herself, while others identified responses for staff and others to pursue. Interestingly, while a number of the participants identified stigma as a systemic issue, very few responses were offered at that level. Most focused on

individual and personal responses, either initiated by the stigmatized person or by mental health workers. Suggestions for the person him/herself included: staying away from the system entirely, self help and peer support, taking responsibility for oneself through attitude adjustment and behavioral strategies, hiding one's history and not hiding one's history.

Major responses which staff and others could initiate included understanding the dynamics of stigma, building rapport with people served, cultivating a sense of mutuality, accentuating the positive, offering chances to exercise responsibility, affording more choices and more control, and creating natural supports.

The inquiry concluded with suggestions for further work, including additional research on each of the areas addressed, as well as a variety of educational and service delivery vehicles to reduce the stigmatizing aspects of mental health programs. The establishment of a Center for the Study of Stigma was proposed. This center could be a valuable focal point for research, education, and promotion of effective program practices. Such a center would be consumer/survivor governed, although it could involve collaboration with supportive researchers, educators and advocates without direct experience as service recipients.

"Stigma is Social Death": Mental Health Consumers/Survivors Talk About Stigma In Their Lives

Background

In 1963, Erving Goffman published his landmark volume, Stigma: Notes on the Management of Spoiled Identity. In it, he explored the phenomena of stigma, which he defined as, "...an attribute that is deeply discrediting..." (p. 3). Such attributes included physical deformities, "blemishes of individual character," or "tribal stigma of race, nation, and religion" (p. 4). Goffman was especially interested in the effects of stigma on interactions between stigmatized persons and those he termed "normals." The consequence of possessing a stigmatizing attribute, he wrote, was that "...an individual who might have been received easily in ordinary social intercourse possesses a trait that can obtrude itself upon attention and turn those of us whom he meets away from him, breaking the claim that his other attributes have on us" (p. 5). In other words, persons with stigmatizing characteristics might be denied acceptance, respect and regard from others whom they encountered.

Since that time, in the field of mental health alone, numerous books, articles, and research projects have continued the exploration of stigma. Scholars in a number of disciplines -- sociology, psychology, history, anthropology -- have contributed to an understanding of the causes and effects of stigma. For example, Link and others (1982, 1983, 1986, 1987a, 1987b, 1989, 1991) have done considerable research in the area of public attitudes and the effects of labeling. Wahl (1976, 1982, 1987, 1989) has also focused on public attitudes and, in particular, on the impact of television on public attitudes. Fabrega (1990, 1991) has done extensive reviews of the literature on psychiatric stigma from the classical to the modern period in western societies. Deegan (1992) has written on the environmental barriers confronting people with psychiatric disabilities -- stigma being one of those -- and on the impact of such barriers on

people's lives. Herman (1985) followed 285 former psychiatric patients living in Canadian society in order to understand how they made sense of their experiences with stigma and what coping strategies they developed.

Sociologists, psychologists and other scholars have also examined stigma from a cross-disciplinary perspective and have added to the body of knowledge on this complex topic. Recent developments along these lines will be summarized in the next section.

In addition to the research and theoretical work on stigma, consumer/survivor, family, and professional advocates have mounted campaigns to "stamp out stigma." Task forces, public forums and conferences have been convened on the topic of stigma.

Despite the many efforts to explore this phenomenon, conversations with consumers/survivors within the mental health field indicate that certain aspects of the topic have not been sufficiently addressed. Stories from stigmatized persons tell of painful experiences of being excluded, rejected and discriminated against, often through hundreds of subtle day-to-day interactions and experiences. Further, people's experiences indicate that many stigmatizing occurrences are related to attitudes and practices occurring within the mental health system itself. While people talk about being stigmatized by family, neighbors, friends, employers, and others, many of their stories point to the mental health service system as a primary source of stigma. Yet little appears in the literature on this topic and virtually no work is being done in the field regarding the subjective experience of stigma and stigmatizing practices in mental health services.

This paper is an attempt to generate thought and discussion on the topic of stigmatizing aspects of mental health programs, largely from the perspective of current and former service users. Its purposes are twofold:

1. To stimulate discussion on the issue.
2. To produce a document which identifies current thinking on the topic and outlines issues for further investigation and action.

It is not intended as a definitive work. Instead, it is a thematic inquiry, an exploration into a topic which has received insufficient scrutiny and yet which often dramatically affects the lives of people involved. It is unabashedly written from the point of view of people who have received or been associated with mental health services. Consequently, the views presented may not seem "objective," if that is defined as without a point of view. In fact, the themes which emerged definitely present a point of view which, at times, may be challenging to absorb. They do not necessarily represent a dispassionate, balanced perspective. But they do represent the experience of a variety of people who, by virtue of their experience, have developed strong views on stigma and on the role of the mental health system and other social services in creating and perpetuating stigma.

Undoubtedly, there are many consumers/survivors who, if asked, would say they are entirely pleased with the services they receive. Some of the people interviewed did have very positive service experiences to relate. But the same people who felt they had benefitted from services also commented on the ways in which those services contributed to their feelings of stigma.

Forty-six people were interviewed. Most interviews were conducted over the telephone and lasted from thirty minutes to one hour. There were several group interviews and one conference call. Participants were selected from lists forwarded by people on the advisory committee¹, and included people from all over the United States. No systematic attempt was made to secure a representative sample, although there was an effort to target varied geographic areas, people from varied racial and ethnic backgrounds, people who were current as well as former service users, and people with a mix of political/ideological orientations.

Of the forty-six people interviewed, thirty-four identified themselves as current or former consumers/survivors. Some of these individuals were also mental health

¹ Please see Appendix A for advisory committee members.

practitioners or professional advocates. Ten participants were family members or professionals who did not identify themselves as consumers/survivors. This second group was interviewed in order to gain additional perspectives on the topic. All interviews with consumers/survivors were completed before interviewing the remaining participants. The themes generated by the first group were used to stimulate discussion with the second group.

The interviews were open-ended. A small number of probe questions were used to generate responses². All participants were very willing to be interviewed. Conversations, as indicated, were quite lengthy. Some participants even called a second time or sent articles, letters, and cassette tapes. A number of people noted that no one had ever asked them about stigma. While some respondents initially found it difficult to articulate their thoughts, once they started talking about their experiences it was sometimes difficult to end the conversation. The interviews generated a great deal of material, only some of which will be included in this report.

Whenever possible, direct quotes are used. Many respondents were willing to have their names used, while others preferred anonymity. For ease of reading, only personal descriptions relevant to respondents' comments will be provided.

The remainder of this report will address the following topics: First, a brief discussion of the dynamics of stigmatization will establish a theoretical framework for the findings of the inquiry. Next, respondents' comments on the sources of stigma in their lives will be described. Then, the attitudes, beliefs, and practices people found to be stigmatizing within mental health services will be discussed at length. Participants' views on the effects of stigma will then be described, followed by responses to stigma that people have found helpful. The report will conclude with recommendations for further work on this topic.

² Please see Appendix B for a list of probe questions.

The Dynamics of Stigmatization

Recent efforts to synthesize the dynamics of stigmatization suggest that it is a set of responses to what Coleman (1986) terms "the dilemma of difference." This dilemma can be stated as follows: It is a fact that all human beings differ from one another in a multitude of ways. Age, gender, skin color, intellectual and social characteristics are but a few of these differences. Although it is a fact of human existence that no two people are exactly alike, certain of these characteristics or attributes become defined as undesired differences or stigmas (Goffman, 1963). Which differences become defined as undesired are, to a certain extent arbitrary. In other words, virtually any difference is potentially a stigma. The particular differences which become defined as undesired are highly dependent upon the social context. Coleman (1986) and others³ assert that stigmas reflect the value judgments of a dominant group, i.e., those possessing power within a given culture. In North America, such values reflect an emphasis on wealth, material prosperity, health and physical beauty, youth, competence, independence, productivity, and achievement (Wolfensberger, 1991). People not seen as reflecting such values are consequently stigmatized.

Ainlay and Crosby (1986) write, "It is shared negative evaluations of human differences that are central to stigma. Individually held biases do not carry the weight of socially designated (hence shared) negative evaluations...societal devaluations are powerful because they cannot be dismissed as the ravings of some idiosyncratic bigot. Instead, they form part of a socially shared sense of `reality.' This characteristic of devaluation is essential for one's very humanness to be questioned (by stigmatizer and stigmatized alike), and as such, these devaluations can be passed on to succeeding generations and woven into the institutional fabric of society" (p. 31).

³ See, for example, Ainlay & Crosby (1986), Becker & Arnold (1986), Goffman (1963), Wolfensberger & Thomas (1983), Wolfensberger (1991).

Coleman (1986) suggests three main causes of stigmatization:

Fear is the primary affective cause of stigmatization. For a variety of reasons, human beings tend to fear differences, fear the future, and fear the unknown. Consequently, they stigmatize that which is different and unknown.

Stereotyping is the primary cognitive process contributing to stigmatization, a result of the human tendency to categorize. Coleman writes, "Stigma appears to be a special and insidious kind of social categorization...People are treated categorically rather than individually, and in the process are devalued. In addition, ...coding people in terms of categories instead of specific attributes allow people to feel that stigmatized persons are fundamentally different and establishes greater psychological and social distance" (p. 219).

Social control is the behavioral impetus for stigmatization. The social control aspect of the stigmatization process serves to preserve the existing social hierarchy -- maintaining stigmatized groups in an inferior social status.

All three of these -- fear, stereotyping, and social control -- may be manifested at the individual and interpersonal levels as well as embedded within our societal structures and institutions.

Coleman then offers an updated definition of stigma:

"To further clarify the definition of stigma, one must differentiate between an `undesired differentness' that is likely to lead to **feelings of stigmatization** (emphasis added) and actual forms of stigmatization. It appears that stigmatization occurs only when the social control component is imposed, or when the undesired differentness leads to some restriction in physical and social mobility and access to opportunities that allow an individual to develop his or her potential. This definition combines the original meaning of stigma with more contemporary connotations and uses" (Coleman, 1986, p. 228).

Stigma is a dynamic process, not a fixed set of attributes. Scott & Miller (1986)

talk about stigmas as "emergent social constructs (which)...require us to investigate how they came to be, what sustains them, and how they may change." Wolfensberger and Thomas (1983), in discussing how stigma is conveyed within a society, assert that it is through the often unconscious process of image association, one of the most effective learning and behavioral control mechanisms known. They state that the symbols and images historically associated with devalued persons are strongly negative and convey messages of illness and death, criminality, worthlessness, incapacity, and others. While these image associations are often made unconsciously, they "nevertheless strongly influence people's role expectancies and the social valuation of the persons so imaged" (p. 27). They describe four service elements ("media") through which images may be conveyed: the physical setting in which a person is associated; groupings with other people and programs; activities of a program; and language, labels and miscellaneous other symbols (e.g., funding sources, laws and regulations, etc.). Further in this paper, the section on "Assumptions, Beliefs, and Practices People Found to be Stigmatizing" will explore some of the negative images participants felt were communicated about them through the various media described above.

How did the participants in this inquiry view the stigmatization process? As with many complex problems, there was a tendency to emphasize one aspect of the process over others, with perspectives varying greatly. Several people believed that stigma was an "inside out" process. Joel Slack said, "...the seed is within ourselves. It takes other insensitive people to validate the stigma." Bill Butler said, "stigma is an inside out thing, not outside in." Others equated stigma with discrimination, and felt that stigma originated in the larger culture. Ron Thompson said, "I don't use the word stigma. I use discrimination. It's exactly the same thing women and blacks face." Judi Chamberlin shared that view. She said, "Even the word 'stigma' is a bad word. The concept of stigma, itself, implies that there's something wrong and we have to hide. We need to talk about discrimination and prejudice. It's a civil rights protection problem." Another participant said, "Stigma can be defined as oppression."

The majority of participants who commented on this saw a dual aspect to stigma-- both internal and external. They felt there was an interaction between what many people termed "internalized stigma" and external conditions of life affecting one's self perception.

Participants' views on the effects of stigma will be described in detail further in the paper. Coleman (1986) identified three major effects: social rejection or isolation, lowered expectations, and "internalized stigma."

Social rejection takes many forms. Systematic social rejection can lead to segregation of people who have been stigmatized. Often this rejection is accompanied by congregation, where people with similar negatively valued qualities are grouped together, as in institutions. Rejection can also be more subtle and interpersonal, such as when people are ignored or treated as if they are not present in social situations, are not consulted about decisions that affect their lives, are excluded from gatherings, and other forms of rejection.

Lowered expectations can result from the stereotyping of stigmatized persons. If a person is seen simply in terms of their undesired difference, or stigma, then they are unlikely to have high expectations held about them. Lowered expectations may prevent stigmatized persons from having opportunities to grow and develop. They may also create and reinforce the low self-esteem that is the hallmark of internalized stigma.

Internalized stigma, as the term implies, refers to the process of absorbing into oneself negative societal beliefs and expectations held about people who are stigmatized. Many people who have been stigmatized consider this the most damaging effect, because it becomes independent of external perceptions, and can consequently follow one through life, regardless of the external evidence of success or achievement.

As will be seen later in the paper, respondents tended to focus on "internalized stigma" as the main effect of stigma. They described feelings and beliefs they held about themselves which then affected their behavior. The impact of lowered expectations and social isolation - especially as initiated by those within the mental

health system - can be noted more strongly in the section on stigmatizing practices.

The next section will describe what participants believed to be the sources of stigma.

Sources of Stigma

People who were interviewed described a number of sources of stigma. Family, friends and intimates were mentioned a number of times. The job market and co-workers were two other often-mentioned sources of stigma. Stigma was considered to be especially strong when respondents attempted to secure positions within mental health programs themselves.

Other people told stories of being stigmatized by neighbors, people at church, and in school. Stigma and discrimination in housing was mentioned as well. Several people mentioned the practices of insurance companies, which they believed were discriminatory. Having to accept the label of mental illness in order to access social security benefits was described by two respondents as stigmatizing.

Additional sources of stigma reported by respondents included: groups of patients who set up a sub-culture, the vocational rehabilitation system, few alternatives for poor people other than acceptance of services, enforced poverty, media and advertising agencies, and generalized societal attitudes which are internalized by people with psychiatric disabilities.

While respondents cited a variety of sources of stigma, most frequently mentioned were the attitudes and practices of the mental health system and its workforce. The following quotes may illustrate the strength of people's response:

"Those who stigmatize most are those in the mental health system. They've shown very little interest in the opinions of former patients regarding the treatment they've received" (Larry Plumlee).

"The whole system is set up (not consciously)...to create and preserve stigma" (Janet Foner).

"I have been involved in the academic world as a professor. They were very non-stigmatizing, they didn't care at all about my mental health background. I have found great stigma in the mental health system" (Anonymous).

"I have this concept in my mind: it's called recovery from treatment. Treatment is the most stigmatizing thing there is" (Anonymous).

"The greater involvement in the system, the greater the stigma" (Bill Butler).

"Stigma in mental health services? It just goes on and on" (Judi Chamberlin).

Respondents who believed that mental health services contributed to stigmatization had many specific examples to relate. These will be described in the next sections.

Assumptions, Beliefs and Practices People Found to be Stigmatizing

Introduction

The dynamics of stigmatization described earlier are manifested in social institutions, including the law, the educational system, social services, etc. No aspects of society are completely free of the three components of stigma: fear, stereotyping, and social control. They are at least as likely to be active within mental health systems and programs as they are in the larger society. While some of these dynamics are conscious and explicit, many others are unconscious and implicit - whether they play out at the interpersonal, organizational, or systemic level. This section will address the practices of mental health professionals, programs, and systems reported by participants to be stigmatizing. Where possible, underlying beliefs or assumptions driving such practices will be explored.

"Staff Hold the Keys:" Power Issues

Issues relating to power and control were most often mentioned as being stigmatizing. Respondents observed that such dynamics permeated the practices of the mental health system. Ron Thompson, whose critique of this paper appears in Appendix C, considered forced treatment to be the practice which "alone guarantees the existence and perpetuation of `stigma'" (Personal communication, January 10, 1993). He said, "Anybody who advocates power over others -- forced treatment -- is for stigma and discrimination."

Comments from other respondents reflected this analysis. A number of people indicated that the practice of "forced" anything -- medication, treatment, hospitalization, activities -- was particularly stigmatizing. One person said, "When there's no coercion, there's no stigma."

In addition to overt coercion, some people mentioned threats -- of forced treatment, or no treatment -- as a strategy to keep people in line. For example, one respondent, who was a voluntary inpatient in a psychiatric hospital, was told that involuntary procedures would be instituted if she left the hospital. Another man said,

"I went to an outpatient psych ward with a prescription written for 'sleep therapy.' The doctor told me that I would just 'sleep for awhile.' This was my 'informed consent' for what years later I learned was electroshock therapy! We were sitting in the hall waiting our turn. Every so often people would be helped out. I saw this man who had a grimace on his face like he was in pain. I walked in, got up on a table. They gave me an injection. I stopped breathing. Then he gave me sodium pentothal and I woke up in another room. I felt like I'd been run over by a truck. I had no energy. I don't know why, but I went back three times. Finally I decided to go talk to the doctor. I went to his office and told the receptionist I can't stand these 'treatments' anymore. Then I heard the doctor's voice from behind the door: 'Tell him if he doesn't do what I say, go somewhere else'" (Anonymous).

Mentioned several times were issues relating to the "ownership" of a person's treatment plan. One person said, "They set a series of goals that the program devises for other people. If the person doesn't like the goals, or if they have goals of their own, they're called 'non-compliant,' or 'rebellious,' or 'unresponsive to treatment'."

Anthony Lehman, a psychiatrist, said, "A care plan that a consumer is 'involved in' is often not collaborative. A person may be presented with the plan, or a brief discussion. If the person doesn't agree, it reverts to a power struggle." Ken Terkelsen, also a psychiatrist, said, "There is an understanding that clients own their plans. But staff feel a responsibility to object or debate aspects of some plans." He commented that, in his view, the tensions surrounding issues of authority and responsibility are ongoing and legitimate (See Appendix D for further comments on this topic.)

Other people described the following practices of programs related to power and control as stigmatizing: restrictions on freedom to come and go, being told when to do things, lack of choice about life decisions, being placed in a house or apartment, staff speaking for people served, having one's preferences, insights, self-knowledge and perspectives ignored. Bill Butler summed it up by saying, "You're not given a choice, you're given a sentence. You're placed in a house, you're placed in an apartment. If you don't have choices that are regular community choices, that is stigmatizing."

Why do issues of power and control pervade the mental health system? As

mentioned earlier in the paper, the stigmatization process is dependent upon the negative evaluations of representatives of a dominant group, i.e., those possessing power within a given culture. Once such negative evaluations are made, representatives of the dominant society are then given license (whether formally or tacitly) to exercise social control over those who fall within stigmatized groups. In mental health services, staff play the part of "controllers" via the myriad of policies, practices, laws, and relationships characterizing the mental health system. This dynamic is further complicated by the expectation that staff be responsible for protecting and nurturing the people whom they serve. As one professional commented, he feels a tension between the "therapeutic agenda and the custodial mandate" that is part of the mental health system's culture.

Status Differential

If there is one category of experiences which captures the essence of the stigmatization process, it is the fact that people with psychiatric disabilities are perceived and treated as having lower status than staff within the mental health system. Coleman (1986), in discussing the meaning of stigma for social relations, writes, "I have intimated that 'stigmatized' and 'non-stigmatized' people are tied together in a perpetual inferior/superior relationship. This relationship is key to understanding the meaning of stigma" (p. 221).

There were many examples of this differential described by respondents. Some were found as symbols or images within the physical environment. For example, one respondent said, "You're shit and I'm not. Why? Because I've got the keys." Other people commented on the presence of separate and more attractive accommodations, such as staff bathrooms and dining rooms, as symbolic of the difference in status.

Other examples of the status difference having to do with interpersonal interactions between staff and consumers/survivors were given. For example, Carmen Meek said, "They feel themselves more well, more together and so they have some right to tell you how to live your life." David Hanlin told the following story: "I think it

(stigma) is worse within the delivery system than it is in the public. For example, a friend went to a five day seminar on mental health issues. Three people stayed in a hotel room: my friend, a therapist, and a social worker. When they found out she was a consumer, they had her reassigned. They said, "We're here to learn about mental illness, to get away. We don't want to be burdened down" -- not only implying that she would be a burden, but also that they, the professionals, were in a position to care for her, even though they had no official role or responsibility in that regard.

Katie Vath, a parent, said, "...the manner in which many professionals speak to (people with) mental illness: the look on the face, the downcast eyes. Even the commissioners. I see this among the professionals: When they're talking to someone with mental illness they speak very loud."

Respondents also gave examples of the status differential as it played out in therapeutic interactions. Interactions in which staff treated consumers as children were cited, as were the use of techniques one might employ with children.

Status differences embedded in program policies and procedures were also described. For example, Stephen Holochuck described an experience where he phoned a mental health center to request a copy of their brochure. The receptionist asked, "Have you received services here?" He responded, "I don't care to answer. Why do you need to know?" The answer was, "Because if you're a professional, we'll mail it to you. If you're a consumer, you have to come in and pick it up."

Tokenism was also cited, on both an individual and an organizational level. Some people mentioned the experience of having their input solicited and then not used. For instance, Janice Herring was part of a committee that was to set up a monitoring system for group homes in her state. She participated in the meeting, gave ideas which the committee agreed to. However, in the report, her ideas had been eliminated.

Pam Goodman, director of a state-wide consumer organization, talked about her experience with organizational tokenism. She said, "Even dealing with other advocacy

organizations...they don't bring consumer organizations into the loop at the same level."

A number of people mentioned the status differential between people with psychiatric disabilities who were hired to work in mental health programs and other workers. Again, this was reflected in personal interactions, as well as embedded within program policies and practice.

Some people talked about the difficulties they experienced during the hiring process itself. For example, Janice Herring said, "The mental health programs I applied to all turned me down. (One place) said there wouldn't be any jobs for three months and they are now interviewing a friend of mine. They ask lots about your mental health history, whereas the business community only wanted to know how you could do the job."

Vera Mellen, a mental health professional, told the story of receiving a phone call from a mental health center about an applicant for a paraprofessional position. The prospective employer asked her a number of questions about the woman's clinical condition. Another participant said that a year after she had been hospitalized, she was looking for a professional position in the mental health field. One person on the board of directors of an agency where she was being considered knew her and her therapist. He called the therapist to ask if she could handle the job.

Beth Stoneking, a professional who was involved in developing a program to employ consumers in a county case management system, shared a number of stories about the stigma experienced by consumers once they were hired to work in the mental health system. For example, when the program was getting started, existing case managers objected strongly to hiring consumers. One of the reasons was, "When are we going to have a release?" In other words, when could professional staff talk about people with psychiatric disabilities without having to be careful of what they said?

Once the program got off the ground, there continued to be circumstances in which the consumer case managers (called service coordinators) were treated differently than professional case managers: There were questions about confidentiality

("Should service coordinators have access to all records or only to `their cases'?" "Should they be allowed to sit through entire case conferences or just the portion concerning `their cases'?") . Service coordinators were also not given their own case loads.

There were questions about disclosure. Case managers felt it was unprofessional, countertransference, a violation of boundaries -- for service coordinators to disclose their experiences as consumers.

Other differences in treatment: The agency risk manager would not allow the service coordinators to drive county cars, even though other volunteers were allowed to. In addition, supervisors met with case managers and service coordinators separately.

Beth Stoneking also described the following response to hiring consumers/survivors: "One program (which employs consumers as case managers) used to have one open room with all case managers. Now the service coordinators - clients - are crammed into one open area and the case managers have their own cubicles...Case managers really had to make sure everyone knew they were the professionals and the service coordinators were the clients. They introduce people as their assistant, and a client."

While this program had numerous examples of status differences between case managers and service coordinators, other respondents also described the stigma they experienced as consumer case managers. Pat Risser, who worked as a consumer case management aide, said, "I was trained as a professional, I worked as a professional, but I was always one rung below on the ladder. We're held to higher standards." He also said, "We had a hard time transitioning into the role as a professional because we were excluded from the social activities of the `normal' staff. We were not treated as social equals. They would go out on Friday nights. When we were finally invited to join the others at their weekly TGIF outings, the barrier of stigma from our co-workers finally broke down, we did socialize when given the opportunity and proved ourselves to

be equally, fully, human. There still remained huge differences in salary and economic status. There remains a long way to go to achieve 'equal pay for equal work.' But, breaking down the social barrier was certainly a step in the right direction."

Pam Goodman gave her perspective on consumer case managers: "They serve as go-fers, do menial work. They aren't part of the treatment team or carrying out peer counselling." Another respondent said, "I'm very concerned that there's a whole movement afoot to hire consumers. They're getting paid half of what other people make. They're neither fish nor fowl."

The effect of stereotypic thinking on the behavior of mental health professionals is strikingly illustrated in the following vignette, shared by David Hanlin: "I went to work as a mental health technician in a psych hospital...I told a nurse about my past psychiatric problems, a trusted co-worker. Next thing I knew, she'd spread this to co-workers. Once they knew, it was amazing the difference in how other staff reacted. They started using patient words on me. Everything I did was 'inappropriate!'"

Why are there such clear examples of discriminatory treatment of consumers who are hired to work within the mental health system? Because the status differential between staff and consumers is deeply embedded within the mental health system as a whole. Until the underlying beliefs and attitudes about people with psychiatric disabilities are addressed within the system as a whole, the employment of consumers/survivors will not be free of such discrimination. Janet Foner summed up the strength of these ingrained beliefs when she said, "From staff, I got opinions that you could never cross that line from patient to staff...They can't believe I'm the same as them...people are made to be pariahs even though they're actually no different than anyone else."

Regimentation and Deindividualization

Some attitudes, beliefs, and practices appear to merely contribute to the stigma that already exists. However, other practices not only perpetuate stigma, but they actively serve to strip a person of their non-stigmatized identity and replace it with the

stigmatized identity of a "mental patient." Regimented and deindividualizing practices of both institutional and community programs are examples. Herman (1985) cites her own and other research⁴ on the chief originator of stigma -- the institutional processing that is a dominant feature of mental hospitalization. Specifically, these include being brought to a hospital against one's will in an ambulance, being treated like an inanimate object, being subjected to an embarrassing physical examination, having one's possessions taken away, staff enforcement of rules and regulations, having intimate information about one's life gathered in the form of case histories (which are then available to all staff), and having enforced interactions with other patients. These processes "...serve to strip the individuals of their prior non-deviant self-conceptions. In its place, the institution offers such persons an alternative conception of self as 'mental patient' -- a deviant identity and status which the persons gradually begin to accept" (Herman, 1985, p. 171).

Respondents in this study gave examples of their experience of regimentation and deindividualization within programs, both institution and community. Specifically, they cited the following:

- Dehumanizing admitting procedures - "During my first hospitalization...the first time I was medicated it was very mortifying. They said I could take it by mouth or injection. I refused, they grabbed me and held me down and injected...Then they took my clothes away. I do not minimize the impact of taking my clothes away. I never got them back. I still remember those -- a yellow shirt with green stripes and green pants...During the first month they didn't allow family, friends and my outpatient psychiatrist...they cut my hair." (Dan Fisher).
- Regimented activities - One respondent described a community day treatment

⁴ Goffman (1961), Herman (1981), Scheff (1967).

program in which he participated where consumers were not allowed to use the bathroom during the entire hour of "group." Other respondents described having to take part in activities (arts and crafts, group therapy) whether they wanted to or not, at fixed times.

- Having to wait for appointments - Anthony Lehman noted that basic routines of clinics don't support self esteem. He commented specifically on the practice of making people wait for appointments or scheduling appointments during the day as if people had nothing better to do. While one interpretation of this phenomena might be that highly valued professionals routinely overbook their appointments, it has a more insidious function of reinforcing messages about consumers that are a consistent theme throughout the entire system -- messages that people are not important, are certainly less important than staff, and that their lives are meaningless.
- Being forced to accept the psychiatric label - "When you go into a psych setting, they get you to admit you're mentally ill and if you don't, they say it's a symptom of your illness. They make you helpless, they break you down. If you're strong and fight back, they'll crush you with drugs and shock treatment and cause further brain damage" (Anonymous). Another respondent wrote, "...it is clear to me that stigmatization is the function of a mental illness diagnosis. There is no way you can claim 'mental illness' without all its legally stigmatizing ramifications."

Separating People from Ordinary Community Life

A number of respondents described the practice of separating people with psychiatric disabilities from ordinary community life as stigmatizing. Several people also commented on the practice of congregating or grouping people with similar labels. Carmen Meek described an event that she experienced as very stigmatizing when she was in a group living situation: "One day we were loaded in the van, they packed lunch for us, and carted us off to a movie. The social worker bought tickets for our group, handed them to the ticket taker and we all trailed in like some group of mental patients."

Another person, critiquing the practices of mental health centers with which he was familiar, said, "Mental health centers group people, isolate them, and set up an

artificial pseudo-environment. They do things outside society, actively set up a segregated society. It is harder for people to improve their quality of life if they can't make it in the society where the rewards come from. Mental health centers reinforce the tendency for people to drop out, stay out, to disengage....The system turns people into monsters. Mental health centers are zoos in the community where mental monsters hang out all day."

Bill Butler referred to segregated housing as the "housing with meals mentality" and said, "segregated housing is the killer."

This practice of segregating and congregating people with psychiatric disabilities exemplifies one of the major effects of stigma described earlier -- social rejection. In addition, it contributes to another of the major effects, lowered expectations. As the respondent above commented, segregation reinforces the tendency for people to disengage from ordinary life, thereby depriving them of opportunities to develop the skills and the confidence to function within a non-segregated environment. As a result, they become viewed as people with no future and little to offer.

Not only is segregation a consequence of stigma, but it also contributes to stigma by reinforcing several stereotypes about people with psychiatric disabilities. These include the belief that people with psychiatric disabilities are fundamentally different than other people, that they "belong with their own kind," that they need to be protected from society, or that society needs to be protected from them.

Non-developmental Approach

The absence of challenge or orientation to growth within the mental health system was also commonly described as stigmatizing. Respondents commented on this feature in the system at large, as well as within programs and individual staff interactions. One respondent said, "There has been, for most of my experience with private and public psychiatry, no rehabilitative approach. I was expected to amount to no more than a clerk even though I have a Ph.D." Several people commented on the underlying beliefs about people with psychiatric disabilities which they felt contributed

to a non-developmental approach. For example, Janet Foner felt that the belief in mental illness as a permanent, chronic, and deteriorating condition was a major factor: "The idea that a `deep emotional upset' can never be recovered from -- that it's an illness that can't be recovered from -- means that people are kept separate, they can never function, will always be impaired. That's the key that keeps the whole thing going...The concept of mental illness as a permanent, chronic condition is stigmatizing."

Carmen Meek said, "The system reminds you of what you can't do: how disabled you are, how ill you are. It doesn't focus on wellness, capability, potential of people."

When describing practices of particular programs, people often referred to their experiences in psychiatric hospitals and day or vocational programs. Several people mentioned the types of activities they found stigmatizing: arts and crafts, children's games, and practice with activities of daily living instead of developing work and social skills. For example, one person said, "The activities in mental health centers were no more than baby sitting - arts and crafts, ADL skills. They were not empowering, a waste of time. They should have vocational services during the day and building socialization skills for after hours."

Pat Risser, who referred to rehabilitation programs which placed people in menial jobs as "food or filth," said, "People are plugged into one or a few slots. They don't really train people to do what they want to do, or find what their potential is." He went on to say, "I went through a severe depression, was in a lot of pain. I said I wanted to do something with my life. Instead of sending me to school as a paralegal, they sent me to a sheltered workshop. I was standing next to someone who was severely retarded and we were counting fish hooks. I was class president in college, I was a law school drop out. If I wasn't depressed going in, that sure did it. I thought, `God, have I sunk that low? Is this what everybody thinks?'"

A couple of family members had the same reaction. Louis Vescio said, "Drop in centers are ill thought out. Drinking coffee and smoking cigarettes is not a program." Leo and Rae Stack, whose daughter had derived great satisfaction from her "regular

job, not a put-up job" noted that some of the so-called work opportunities they had heard about were detrimental to the people because of the demeaning limitations placed upon people. Katie Vath, who served on the board of a psycho-social rehabilitation agency with an excellent reputation, said, "...the attitude of these people is that about the only thing the mentally ill can do is scrub floors, empty trash cans and dust desks." These non-developmentally oriented programs reflected the perception that service users had little potential.

Other respondents described interactions with staff that reinforced low expectations and the view of people as having limited potential. One person said, "One case manager spent most of our time together convincing me that I should accept my devalued status and that I should accept part-time janitorial work as a future...accept my disabled and unabledness." This same person is now working full-time in mental health administration at a state level.

The results of this non-developmental approach? "Massive dependency" (Carmen Meek), "low self-esteem/low self-confidence" (Anonymous), and finally, no hope: "The system tends to foster no growth. This no fault thing encourages no growth: 'This is the way you are, nothing can change,' 'incurable,' 'lifetime,' 'once you've got it, you're stuck'" (Anonymous).

"Life in a Fishbowl"

The lack of respect for a person's privacy was seen by a number of respondents as stigmatizing. In fact, more than once, people referred to this experience as "life in a fishbowl." This sense of always being observed was commented upon by several different people. Joel Stanley said, "All the agencies I've ever had to see, they must talk. They look at me strange and move away." Paul Ottenstein said, "People are always observing your behavior. You have to be careful about what you do..." A third person said, "Going in and telling a perfect stranger the most intimate experiences of your life -- opening up your private self and then just getting battered -- it's very destructive."

Combined with the experience of always being observed by staff was the sense that one's behavior was "overinterpreted" -- in other words, that any normal feelings or behavior were interpreted as pathology or symptoms of one's illness. As Larry Plumlee, a professional said, "The stigma I hear the most is because you are a former mental patient, any emotional expression or statement you make is interpreted as a manifestation of illness." Pam Goodman, director of a state-wide advocacy organization, said, "Once I took this job, I experienced a lot of stigma. It was a token organization, barely funded. I started attending meetings. I was discounted, condescended to, treated as a consumer. People talked down to me. I served on a committee which had to do with evaluation and measurement. I have a Ph.D. in that field. I was putting out state-of-the-art ideas but I must have gotten too enthusiastic. I actually got patted down."

Amy, who coined the term "over-interpreted behavior," described her experience during a hospitalization. She related that during her time in the hospital, she chose to be very quiet ("I didn't trust them. I wasn't going to tell them life's deepest secrets because I didn't know how it would be twisted, used against me.") However, she was much more animated when she made phone calls to her friends and family. Consequently, in her case record was written: "Question manipulative affect. Brighter when on phone."

Other examples:

Regarding people who spoke up for themselves: "Maybe we should increase your medications."

Regarding someone who was very tired: "Are you sure you're not toxic on Lithium?"

One consequence of this was the stifling of ordinary emotions. Janice Herring said, "`Calm down, calm down': When I get mad my contributions aren't taken seriously." Carmen Meek, in speaking about her personal relationships, reported, "If you get angry, irritated, have feelings, there's a question of `Did you take your pill?'"

You're not allowed to express your feelings, or to have normal human reactions."

Larry Plumlee said, "There is much more of a ban on feelings in mental hospitals. It points to a basic problem in psychiatry: Angry equals paranoid; showing grief equals depressed. Behaviors that enable people to heal are labeled as symptoms of disease."

A systemic manifestation of having one's behavior over-interpreted was the practice of having one's life viewed through the "lens of diagnosis" rather than poverty. Some respondents felt that the consequences of poverty played a much larger part in influencing life conditions than did the psychiatric disability. Yet the struggles and challenges they experienced were treated as manifestations of their illness rather than poverty.

This phenomena, being watched and having one's behavior interpreted as evidence of pathology, illustrates two components of the stigmatization process -- social control and stereotyping.

Who experiences "life in a fishbowl"? With the possible exception of celebrities and royalty, it is usually those people who are subjugated, or under the control of others, who are closely watched. The consequent "over-interpreted behavior" exemplifies the stereotyping process which occurs to stigmatized individuals: The stigma assumes a "master status" (Goffman, 1963), and all other aspects of the person are either overlooked or interpreted to confirm that master status.

Inadequate Access to Information

Some respondents indicated that they felt inadequate access to information was stigmatizing, both to people with psychiatric disabilities and their families. Specifically mentioned was failure to educate consumers regarding their diagnosis or prognosis as well as what one person described as the "unduly mystifying process" of therapy.

What underlying beliefs about people might these practices reflect? One possibility is that people with psychiatric disabilities are not seen as capable of understanding their diagnosis or prognosis because they are lacking in awareness. Some respondents commented on the perception that mental illness causes people to

be disconnected from the real world: "Most resounding is the perception by care givers that an individual who is really sick is not connected to the real world in any way. But we can always sense the disrespect and insensitivity around us" (Joel Slack).

Another person said, "Just because I'm chewing on a table doesn't mean I don't know I'm chewing on a table."

Another possibility is that is people with psychiatric disabilities are seen as too fragile to cope with the "reality" of their diagnosis and must be protected from that knowledge.

Yet a third possibility is that people are seen as merely objects which need to be fixed and, as persons, are irrelevant to the process of treatment. A number of people commented on this perception:

- "An assumption is underlying the whole system: there are people who need fixing and the fixers. It runs through the whole system, community and hospital" (Janet Foner).
- "A lot of psychology, especially behavior modification, objectifies people. Instead of believing people can learn and grow, it's `you have to do something to a person'" (Janet Foner).
- "Training is oriented to seeing a patient as an object, passive. `Placing people' - moving them around makes them sound like rocks" (Anthony Lehman).
- "You're treated as if you have a physical ailment that a medical system has total control over: Isolate symptom, control environment -- to treat a condition that has no scientific proof" (Anonymous).

Lack of Attention to Personal Characteristics Which May be Stigmatizing

A small number of people mentioned aspects of life which, while they might not be under the direct influence of programs, do constitute "media" through which stigma is communicated, as discussed earlier in the paper. As such, these areas need to be considered and possibly addressed by mental health workers.

For instance, one person commented that effects of drugs cause funny

movements which draw undue attention to the person. Another person wrote, "Treatment with drugs often makes invisible suffering visible."

A couple of people referred to the clothing and behavior of consumers ("For four and a half years I was institutionalized, right down to the clothes I wore. It set me apart.") Although program staff may not be directly responsible for causing these stigmatizing aspects of a person's identity, they do have a responsibility to support individuals who wish to address them. As Joel Slack said, "...care givers have both the responsibility and the capacity to remove stigma..." In addition, staff have the responsibility to offer feedback to people when aspects of their behavior and/or appearance interfere with achieving other goals they may have, such as employment, personal relationships, being accepted in the community, etc.

Language and Labeling

Respondents' comments about language and labeling fell into seven categories:

1. Objections to language separating the phenomena of stigma from the larger dynamics of oppression: Some respondents were adamant about using words such as "prejudice," "oppression" or "discrimination" to describe the phenomena being addressed, rather than using the word "stigma." As mentioned earlier, Judi Chamberlin said, "Even the word 'stigma' is a bad word. The concept of stigma, itself, implies that there's something wrong and we have to hide. We need to talk about discrimination and prejudice. It's a civil rights protection problem."
2. Objections to offensive slang: Words such as "twisted," "nut," "cripple," "moron" were seen as stigmatizing.
3. Objections to patronizing or condescending language: Some people commented on the practice of referring to people as "our" mentally ill or "the" mentally ill. Other people talked about patronizing tones of voices, or those which might be used in talking to children.

4. Objections to euphemistic language: One person said, "Psycho-babble like 'We're waiting for the therapeutic effect' bothers me." Another person felt the word 'consumer' was euphemistic: "They changed the language, but they didn't change the practice. It's a lie. There's no market research, the products aren't changed."
5. Objections to language with a medical orientation: Words such as "patients," "mental illness," "sick," were seen as stigmatizing by some respondents, along with the "language regarding symptomology that makes it sound like people have mold growing out of their ears," as Anthony Lehman said. "Decompensating" might be a good example.
6. Objections to language with the implicit assumption of the power to judge: Terms such as "treatment resistant," "high or low functioning," "non-compliant," "rebellious," "unresponsive to treatment," and similar terms, which tended to pass judgment, were considered stigmatizing by a number of people.
7. Objections to dehumanizing language: Very few people commented specifically on the use of dehumanizing language. One respondent said he felt the term "placing people" was stigmatizing people because it was as if the people were rocks -- inanimate objects.

Harriet Lefley, a professional and a family member, felt that the way various terms are perceived should be changed, rather than the terms themselves: "A big problem with the whole stigma issue is that everybody has bought in to the stigmatizing properties of all the terms surrounding mental illness. It's taken us many years to say, 'I have cancer.' Why can't we do that with mental illness? Why can't we proudly say, 'I have a mental illness and I've transcended the barriers'?"

There were few non-stigmatizing alternatives offered to the terms people objected to. Several people proposed that the word 'stigma' being discontinued and that 'discrimination,' 'prejudice,' or 'oppression' take its place. Judi Chamberlin proposed that language referring to people with psychiatric disabilities and their roles within the system be considered in context. She said, "You are a client in a program, a member in a clubhouse, and a survivor in the political context."

Other Practices

"Second-hand Services"

Another theme was the perception that mental health services were "second-hand." Some people commented that they had experienced services as low quality or had received therapy from unqualified staff. A couple of people commented on the location of programs in poor neighborhoods or rundown environments. Not only are such practices evidence of the devalued or stigmatized status of service users, but they also contribute to the stigma, by conveying the impression that people with psychiatric disabilities do not "deserve" quality services, or environments. The association then made between the people and the services/environments is that the people themselves are second hand or second rate.

Cues in Physical Environment from Asylum Era

Ken Terkelsen referred to cues in the physical environment inherited from the asylum era. These cues included such practices as locking up knives, padlocking refrigerators or medication closets, covered radiators, etc. By and large, such cues represent an overprotective orientation to service -- the belief that people might hurt themselves if they had access to such items.

Effects

Earlier in the paper, three main effects of stigma -- social rejection/isolation, lowered expectations, and internalized stigma -- were introduced. In this section, respondents' comments on the effects of stigma will be explored in more depth. Most people focused on "internalized stigma" and consequent feelings and behavior.

An often-mentioned effect was lowered self-esteem. For example, Dan Fisher 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." Leonard Laird said, "You get nailed down, they label you, you're under their jurisdiction, you're a dummy...It made me feel helpless, hopeless. Now I don't feel that way, I just said, 'To hell with them, they can jump in the ocean.'

What changed? My self-esteem, my confidence. I know who I am."

Anthony Lehman said, "Stigma erodes self-esteem. Self esteem that is very seriously damaged leads to people not trying, trying to kill themselves, or being destructive with their lives. They destroy their chances because they're angry and feel so bad."

Other people mentioned anger as well. Janice Herring said, "I'm angry. I want to walk away from the consumer movement completely. I can't continue to fight what appears to be a lost cause." Another person said, "I talk to myself, often angrily. It makes you feel like you're a mental patient, you're abnormal."

Depression was another effect of stigma, although one respondent said, "I've been psychologized so much, it's ridiculous! I'm helpless, hopeless, lost, frustrated, discouraged, confused -- not depressed."

A number of respondents described the feeling that they carried a life-time label that was all-encompassing. One person, who has a Ph.D. and is teaching university at the graduate level, said, "It's been only the last two or three years that I stopped calling myself 'crazy'. Yet my last hospitalization was in 1980. I used to say, 'Oh, you can't do that because you're crazy.'"

Another man said, "I became super sensitive to anything unusual about myself. I became hypernormal. I would never make any references to interpersonal violence around professionals, even jokingly, because of the presumption of violence."

A heightened sense of vulnerability was mentioned by other people. One man said, "I can actually sense people's attitudes changing toward me. You turn to things to close that vulnerability -- booze, drugs, etc. -- but it makes things worse." Paul Ottenstein said, "There is a sense of vulnerability when you've been a patient. You feel like people are picking up on that and are more critical of you. It's a result of stigma."

Perhaps as a consequence of the erosion of self-esteem, some people found it difficult to take charge of their lives. Paul Ottenstein said, "A lot of times, people internalize the stigma and the label means more than it should. It doesn't change you

personally, but it makes it more difficult to find your own voice and make changes in your own life."

Another consequence was described by one man as a "mindset of degradation." He said, "This is a mindset a lot of us get into because of our label. It degrades us, makes us not care what we look like. It adds to the shiftlessness, allows us to accept being grouped with other mental patients and being publicly identified."

Respondents described a number of other effects of internalized stigma. The stifling of growth, productivity, and desire to participate in growth-supporting activities was mentioned by a number of people. For example, Neil Robinson wrote, "The first effect stigma had on me was to cause me to withdraw from activities that could have contributed to my recovery process. My recovery may have been delayed a little, but eventually I was able to see that I needed to participate and take on roles in the community mental health system to provide others with a role model while building my own confidence and changing attitudes of professionals and the general public."

Another effect on the behavior of stigmatized persons was the process of "learning to walk on eggshells," in other words, learning to act like a mental patient: "Speaking softly, being nice, agreeing with others, losing a sense of what one thinks or only remembering it in the middle of the night, certainly not when with people who assert some authority," was how Larry Plumlee described it.

The presentation of oneself in public was also affected, leading to lost opportunities in employment, education, and relationships. Anthony Lehman said, "Stigma leads to self-consciousness in public situations. (People wonder), 'How do I manage it if it comes up?' Some gets mixed up with the mental illness, paranoia, etc., but a lot of it is the effect of stigma."

Others discussed the social isolation they felt. When asked about the impact of stigma, Janet Foner said, "In the first year after my hospitalization, I thought my life was over. I was an outcast. I experienced life as extremely limiting, depressing, deadening, over, the end of the line. I thought I couldn't go out of the house, talk to

anyone, leave my parents' house. I thought of myself as incapable."

Also mentioned was the sense of feeling alone, burdened, and different. Joel Stanley said, "I feel like I'm alone and carrying this big burden. I will probably will never have a life like everybody else, get married, have kids, have a house...I feel that I'm over the hill, all used up, nobody's interested in me on any level."

Relationships with family and friends were also affected. For example, one man felt a deep sense of isolation as a consequence of stigma. He said, "The major consequence of stigma is social death. The only social environment people have is the mental health center. They live in isolation, don't have people to talk to, often can't afford a phone. This isolation contributes to ongoing crises people have. Their spirit doesn't want to die and eventually people fight back."

"Fighting back" was one of the responses to stigma suggested by participants. In the next section, other responses will be described as well.

Responses

Participants had many suggestions about responding to experiences of stigma. Some of the suggestions focused on strategies which might be used by the stigmatized person him or herself, while others identified responses for staff and others to pursue. Interestingly, while a number of the participants identified stigma as a systemic issue, very few responses were offered at that level. Most focused on individual and personal responses, initiated either by the stigmatized person or by mental health workers.

Responses Initiated by the Stigmatized Person

Stay away from the mental health system entirely. Some participants felt that any contact with the mental health system would stigmatize them without offering corresponding benefits. Stephen Holochuck suggested what he called "radical disengagement:" "You want to have minimal contact with professionals. Don't let them make the parameters of your reality. Don't get invested enough to fight with them." Another person advised that people "never ever go for any kind of mental treatment, even if it's just talking," while a third person recommended that people walk away from

services.

This response acknowledges the systemic nature of stigma as well as its power. Rather than suggesting people "fight the system," the recommendation is that people stay as far away from the system as possible in order to avoid stigma. This view is consistent with observations offered earlier that "the whole system is set up...to create and preserve stigma," and "...stigmatization is the function of a mental illness diagnosis. There is no way you can claim 'mental illness' without all its legally stigmatizing ramifications."

Self help and peer support. Other participants recommended contact with others who had had similar experiences, through self help and peer support. In fact, Judi Chamberlin attributed her minimal experience with stigma to being open about her identity and active in the movement. She said, "My experience has been pretty unusual because I've been so open about it. I got to write a book, travel and speak. Why was my experience different? Being part of a movement, part of a group...seeing it as a rights issue from the very beginning." This suggestion derives from the perspective that stigma and the stigmatization process are forms of oppression which can be addressed through consciousness-raising and joining together with other affected persons.

Take personal responsibility for addressing stigma -- attitude adjustment. Some respondents felt that coming to terms with the fact that most stigma comes from within was the first step to removing it. Joel Slack said, "Just as stigma begins with ourselves, it must end with ourselves."

Bill Butler advised people to "get off that SSI/SSDI mentality." He also said, "Important messages: Think on your own. Trust your gut. Don't do things until they're ready for you."

Take personal responsibility for addressing stigma -- behavioral strategies. A number of behavioral strategies which also focused on assuming

personal responsibility were suggested. Some examples:

- Do a personal inventory: If you want to be part of things, if you want to be accepted, ask yourself, "What behaviors set me apart from others?"
- Do ordinary things, do things that make you feel good: Cook a great meal, have a party, help others, think of happy memories, get involved in sports, join groups.
- Focus on total healing.

As with the responses above, these strategies may improve an individual person's circumstances but do not address systemic stigma.

Hide your history. Some participants advised that people with psychiatric labels refrain from telling anyone. Others advocated selective "telling." However, the opposite approach was recommended by other participants.

Don't hide your history. Judi Chamberlin, whose experience was summarized above, said, "I have not experienced a whole lot of stigma myself, once I stopped hiding. Hiding is internalized oppression. Most of the time it's a positive experience. If someone goes public, there's no way to blackmail. When I first went with Mental Patients' Liberation Front, we got a chance to go on radio and (we) used fake names. Then we asked, 'If we use fake names, what does that say about our message?' That was a turning point."

Responses Originating from Staff and Others

Understand the dynamics of stigma. Earlier, Joel Slack was quoted as saying that people with disabilities must take responsibility to address stigma. However, he also felt strongly that staff have responsibility to create an environment where stigma cannot spread. He said, "In a therapeutic environment, if staff understand stigma and its dynamics they can keep it from growing."

In order to better understand stigma and its dynamics, Ken Terkelsen suggested that providers create a "culture of self-examination." This might take the form of an

inventory of what is happening to foster or eliminate stigma within a program.

Build rapport with people served. Having relationships based on trust and responsiveness were mentioned by a number of people as effective responses to stigma. Feeling "heard" by staff was an important experience to people. Some participants suggested giving people more chances to talk, and focusing on building rapport with a single person rather than feeling like one had to treat all people served identically. Also mentioned was one of the most basic strategies to respond to stigma: Treat people as human beings.

Joel Slack said, "Staff don't understand stigma the first time they treat people disrespectfully or as if they're different. They're encouraging stigma to grow. If, for some reason, stigma is growing in someone in one environment and they get transferred to another environment, care givers have both the responsibility and capacity to remove stigma by treating people with great respect and dignity."

While these recommendations contribute to valuing the person and treating them with respect and dignity, they do not address the social control aspect of stigma since it is possible to treat one's subordinates with respect and dignity. In fact, as Supeene (1990) writes, people who are treated with dignity while remaining in a subordinate position can experience great conflict: "The conflict lay between the staff's friendliness on the one hand, and their authority on the other. Because they could be supportive listeners I felt respected and cared for. But they were also the 'experts' and they were in authority; therefore they had the final say on what my problems really were and what would be done about them, so I felt diminished and helpless" (p.34).

Cultivate a sense of mutuality. Some people recommended that staff share their own challenges and difficulties in order to relate to people on a more equal level.

Accentuate the positive. This, and the related strategies which follow, are effective responses to non-developmental attitudes and practices identified by participants as stigmatizing. Carmen Meek said, "The system lacks motivational tools for people who want to do stuff for themselves. When you do get diagnosed, your self-

esteem is totally shot. The thing that works is to build people up." She recommended focusing on wellness, capability, and potential of people. Another respondent stressed the importance of high expectations. Related to the above strategy, other respondents recommended that people be given chances to exercise responsibility.

Chances to exercise responsibility. One participant related this personal transformation from a "mental patient identity" to someone who feels good about himself: "Since I've had this job (working as an advocate in a recipient-run program) I developed skills, started feeling good about myself. I do a lot of grant writing. I'm developing programs. I'm free to do what I want to do, handle a lot of responsibility. I feel like I'm doing something important."

More choices, more control. Providing opportunities to have more control over one's life was a commonly mentioned way of reducing stigma. Respondents recommended that this be adopted in a number of ways, including attitudes and roles of staff, more choice and control for consumers within existing programs, and fundamental change that focused on eliminating coercive treatment.

In terms of attitudes and roles of staff, one respondent recommended that providers ask service recipients, "How can I help?" People suggested that consumers be assisted to play a greater part in determining their own services and staff see themselves as consultants to that process.

In terms of greater control within existing programs, a number of recommendations were made. Specific areas included trusting people to take their own medication, affording opportunities to establish a schedule that fits one's own life, and providing more choices in activities. In addition, consumer perspectives on case notes and reports were mentioned. At the systemic level, consumer participation and leadership in decision-making on an individual, program, and systems level was recommended as an antidote to stigma.

More fundamentally, some participants advocated the elimination of coercion within mental health services as a way of eliminating stigma. One participant said, "No

coercion = no stigma." Ron Thompson, who believes that "forced treatment" is a contradiction in terms, recommended that the two be separated conceptually. He said, "...two things are tied together that shouldn't: force -- involuntarism -- and the practice of medicine...When I say I'm against forced treatment, people hear me saying two things I didn't say: (That) I'm against treatment and (that) I'm against coercion."

Create natural supports. Several participants advocated that connections with family, friends, and other community members be fostered. Carmen Meek said, "There's a difference between the artificial support network of a therapist and the support provided by family or friends. You're paying those people to be your support. It's not normal. The system needs to create natural supports. The system thinks of itself as, 'We're what people need to get well.' What people need is family, friends and the community."

Other. A number of other strategies were mentioned as well, including: Ongoing support following consciousness-raising, allowing people to experience hard times rather than attempting to prevent them, providing incentives rather than punishment for growth, community education, and a focus on the unique and individual qualities of each person.

Suggestions for Further Work

Judging from the responsiveness of participants, this is an important topic for further work. Intended as an inquiry, the project developed into a much larger undertaking than initially planned. As the hours spent on the project multiplied, the enormity of the topic became increasingly clear. There is considerably more work, both academic and applied, to be undertaken. Below are some suggestions:

Further Research

A comprehensive literature review. In conducting this inquiry, a number of relevant books and articles were identified. While it was beyond the scope of the project to fully incorporate relevant literature, it would be a very beneficial undertaking for a larger-scale project.

More detailed research on topics addressed in this inquiry. All of the areas explored in this paper would benefit from examination in more depth. For example, it would be useful to interview current service users and compare their perceptions with those of former service users, to catalogue in detail specific features of programs thought to be stigmatizing, to thoroughly identify practices which are non-stigmatizing, to explore how programs can successfully change their practices, etc.

A thorough exploration of the theoretical material introduced in the paper and its relation to program practices would be especially helpful. For example, how do the three causes of stigma - fear, stereotyping, and social control - contribute to each of the practices identified as stigmatizing? Where ever possible, I have offered some hypotheses, but they are preliminary. What interventions might address each of the three causes of stigma?

Catalogue Existing Interventions and Educational Materials

Finding out what people around the country are doing to respond to stigma, and, in particular, to address practices of mental health programs, would be a useful undertaking. Although there is not a great deal of work in existence, there are undoubtedly people working on this topic.

Further Education

Many arenas and audiences could benefit from education: Mental health professionals, people with disabilities, family members, administrators, community members, and faculties in higher education programs that train professionals. Not only are new educational materials needed, but, perhaps more importantly, access to these audiences must be developed. This will require considerable persuasion and advocacy in order to generate interest and openness to the topic.

Promotion of Effective Practices

Again, there are many areas to pursue. Some examples: focus groups; advocacy; technical assistance; community education forums; writing books with people affected by stigma which combine theory and practice; etc. Piloting an approach to

service delivery which is non-stigmatizing would be especially helpful. Most of the strategies for addressing stigma offered in the previous section address only one of the elements of stigma, and are insufficient alone. Perhaps a useful exercise would be the design of a multi-pronged approach to addressing stigma within mental health services.

Center for the Study of Stigma

One possible vehicle for implementing at least some of the above would be the establishment of a center for the study of stigma. While apparently there already exist several stigma clearinghouses in the United States, this center could be a valuable focal point for research, education, and promotion of effective program practices. Such a center would be consumer/survivor governed, although it could involve collaboration with supportive researchers, educators and advocates without direct experience as service recipients. For example, much of the theoretical material in this paper draws upon the work of a group of researchers who came together in the early 1980s at a summer institute on Stigma and Interpersonal Relations. This multi-disciplinary forum addressed stigma from a number of perspectives,

thereby enriching our understanding of the phenomenon.

The Center for the Study of Stigma could be either national or regional in scope. Its main benefits would be the capacity to link research, education, and promotion of practice in an integrated fashion; its presence as a focal point to coordinate efforts to address stigma; and its symbolic value, encouraging sustained activity in this area.

Conclusion

In his interview, Joel Stanley said, "I'm struggling for existence like everyone else...to exist with dignity and hopes, to carve out a niche for myself, to live with some enjoyment, to find some people who will treat me decently." These are realistic goals for a lifetime, goals that most of us would share. Yet, as we have seen, there are

many factors which stand in the way of achieving these goals for people who have experienced stigma or discrimination.

Coleman (1986) writes, "when people find it necessary or beneficial to perceive the fundamental similarities they share with stigmatized people rather than the differences, we will see the beginnings of a real elimination of stigma" (p. 229). It's time we tackle the economic, psychological and social barriers to seeing these fundamental similarities, at least within the mental health system.

References

- Ainlay, S. C., & Crosby, F. (1986). Stigma, justice and the dilemma of difference. In S. C. Ainlay, G. Becker, & L. M. Coleman (Eds.), The dilemma of difference (pp. 17-38). New York: Plenum Press.
- Becker, G., & Arnold, R. (1986). Stigma as a social and cultural construct. In S. C. Ainlay, G. Becker, & L. M. Coleman (Eds.), The dilemma of difference (pp. 39-58). New York: Plenum Press.
- Coleman, L. M. (1986). Stigma: An enigma demystified. In S. C. Ainlay, G. Becker, & L. M. Coleman (Eds.), The dilemma of difference (pp. 211-232). New York: Plenum Press.
- Deegan, P. E. (1992). The independent living movement and people with psychiatric disabilities: Taking back control over our own lives. Psychosocial Rehabilitation Journal, 15(3), 3-19.
- Fabrega, H., Jr. (1990). Psychiatric stigma in the classical and medieval period: A review of the literature. Comprehensive Psychiatry, 31(4), 289-306.
- Fabrega, H. Jr. (1991). The culture and history of psychiatric stigma in early modern and modern western societies: A review of recent literature. Comprehensive Psychiatry, 32(2), 97-119.
- Goffman, E. (1961). Asylums: Essays on the social situation of mental patients and other inmates. Garden City, NY: Anchor.
- Goffman, E. (1963). Stigma: Notes on the management of spoiled identity. New York: Simon & Schuster, Inc.
- Herman, N.J. (1981). The Making of a Mental Patient...Unpublished masters thesis, Canada.
- Herman, N. J. (1985). Crazies in the community: An ethnographic study of ex-psychiatric clients in Canadian society -- Stigma, management strategies, and identity transformation. Unpublished doctoral dissertation, McMaster University, Canada.

- Link, B. (1982). Mental patient status, work and income: An examination of the effects of a psychiatric label. American Sociological Review, 47, 202-215.
- Link, B. (1987a). Understanding labeling effects in the areas of mental disorders: An assessment of the effects of expectations of rejection. American Sociological Review, 52, 96-112.
- Link, B., & Cullen, F. (1983). Reconsidering the social rejection of ex-mental patients: Levels of attitudinal response. American Journal of Community Psychology, 11(3), 261-273.
- Link, B., & Cullen, F. (1986). Contact with the mentally ill and perceptions of how dangerous they are. Journal of Health and Social Behavior, 27, 289-303.
- Link, B. G., Cullen, F. T., Frank, J., & Wozniak, J. F. (1987b). The social rejection of former mental patients: Understanding why labels matter. American Journal of Sociology, 92(6), 1461-1500.
- Link, B. G., Cullen, F. T., Struening, E., Shrout, P. E., & Dohrenwend, B. P. (1989). A modified labeling theory approach to mental disorders: An empirical assessment. American Sociological Review, 54, 400-423.
- Link, B. G., Mirotznik, J., & Cullen, F. T. (1991). The effectiveness of stigma coping orientations: Can negative consequences of mental illness labeling be avoided? Journal of Health and Social Behavior, 32, 302-320.
- Scheff, T. (1967). Mental Illness and Social Processes. N.Y.: Harper and Row.
- Scott, R. A., & Miller, D. T. (1986). Foreword. In S. C. Ainsley, G. Becker, & L. M. Coleman (Eds.), The dilemma of difference (pp. ix-xiii). New York: Plenum Press.
- Supeene, S. L. (1990). As for the sky, falling: A critical look at psychiatry and suffering. Toronto: Second Story Press.

Wahl, O. (1976, March 13). Six t.v. myths about mental illness. TV Guide, pp. 4-8.

analysis of service systems' implementation of normalization goals. Downsview, Ontario: Canada.

Wahl, O. F. (1987). Public vs. professional conceptions of schizophrenia. Journal of Community Psychology, 15, 285-291.

Wahl, O. F., & Lefkowitz, J. Y. (1989). Impact of a television film on attitudes toward mental illness. American Journal of Community Psychology, 17(4), 521-528.

Wahl, O., & Roth, R. (1982). Television images of mental illness: Results of a metropolitan Washington media watch. Journal of Broadcasting, 26(2), 599-605.

Wolfensberger, W. (1991). A brief introduction to Social Role Valorization as a high-order concept for structuring human services. Syracuse, NY: Training Institute for Human Service Planning, Leadership and Change Agency (Syracuse University).

Wolfensberger, W., & Thomas, S. (1983). PASSING: Program

Appendix A
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Appendix B

Interviews with current or ex-patients asked the following probe questions:

1. Please tell me a little about your background and, in particular, your experiences with the mental health system.
2. Have you ever experienced stigma? In what areas of your life?
3. Do mental health services contribute to stigma? In what ways?
4. What are the effects of stigma in your life (behaviorally and emotionally)?

The questions asked family members, advocates, and professionals were more direct since they were conducted after many interviews with ex-patients were completed. The following questions were asked:

1. What is your involvement with the mental health system?
2. Are service users stigmatized by practices of mental health programs? If so, in what ways?
3. What is the impact?

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While I am painfully aware of the shortcoming of this inquiry, I only hope it will stimulate others to add their contributions.