Mental Health Consumers' Experience of Stigma

by Otto F. Wahl

Abstract

The extent to which mental health consumers encounter stigma in their daily lives is a matter of substantial importance for their recovery and quality of life. This article summarizes the results of a nationwide survey of 1,301 mental health consumers concerning their experience of stigma and discrimination. Survey results and followup interviews with 100 respondents revealed experience of stigma from a variety of sources, including communities, families, churches, coworkers, and mental health caregivers. The majority of respondents tended to try to conceal their disorders and worried a great deal that others would find out about their psychiatric status and treat them unfavorably. They reported discouragement, hurt, anger, and lowered self-esteem as results of their experiences, and they urged public education as a means for reducing stigma. Some reported that involvement in advocacy and speaking out when stigma and discrimination were encountered helped them to cope with stigma. Limitations to generalization of results include the self-selection, relatively high functioning of participants, and respondent connections to a specific advocacy organization—the National Alliance for the Mentally Ill.

Key Words: Mental illness, stigma, discrimination, mental health consumers.

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Mental illness stigma is a matter of great concern to mental health advocates. Negative responses to people who have been identified as having a mental illness are seen as a major obstacle to recovery, limiting opportunities and undermining self-esteem (Fink and Tasman 1992). Not surprisingly, stigma also has been the subject of substantial social science research. Seminal work by Erving Goffman (1963) and Thomas Scheff (1966) described the stigmatizing process that may follow from being identified as having a mental illness, and numerous research studies have attempted to demonstrate the unfavorable effects of mental illness labeling.

One type of stigma research involves self-reports from the general public. Population samples are asked to state their opinions about mental illness and people with mental illnesses (e.g., Nunnally 1961). Other public opinion studies present specific statements about mental illness and ask respondents where they stand with respect to those statements (e.g., Cohen and Struening 1962; Taylor and Dear 1981; Yankelovich 1990; Beldon and Russonello 1996). Early studies revealed strikingly negative attitudes toward mental illness (see Rabkin 1974). More recent surveys suggest improved attitudes: the majority of people in a 1993 *Parade Magazine* survey, for example, agree that "more tax money should be devoted to caring for the mentally ill" (Clements 1993) and 60 percent of those in another survey (Beldon and Russonello 1996) say they would support a group home for people with mental illness in their neighborhood.

Another type of stigma study uses vignettes or profiles of individuals and study participants' ratings of the people described. Identical descriptions of behavior were found to produce more social rejection, more fear, and more negative expectations when they were accompanied by information that the individual being described has a history of psychiatric disorder or treatment (Whatley 1959; Philips 1966; Neff and Husaini 1985; Purvis et al. 1988; Riskind and Wahl 1992).

Finally, there are analog behavior studies, in which people are led to believe they are dealing with a person with mental illness. Such studies fairly consistently find that inclusion of information about past psychiatric treatment leads to decreased success in applying for housing, employment, and school admission, and that identification as a patient leads to condescension and biased interpretation of behavior on the part of others, including mental

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health professionals (Farina and Felner 1973; Farina et al. 1973; Rosenhan 1973; Page 1977; Dovidio et al. 1985; Sibicky and Dovidio 1986; Oppenheimer and Miller 1988). More extensive reviews of these three types of studies and their results have been provided by Rabkin (1974) and Link et al. (1992).

What is conspicuously absent from these explorations of mental illness stigma is the mental health consumer—the person with the mental disorder who is presumably the recipient of stigma. The relatively few studies that have sought information directly from mental health consumers provide evidence that they experience themselves as stigmatized (e.g., Campbell and Schraiber 1989; Mansouri and Dowell 1989; Herman 1993), expect to be treated poorly by the public (e.g., Link 1987; Link et al. 1989), encounter rejection and discrimination (e.g., Herman 1993; Link et al. 1997), suffer demoralization and reduced life satisfaction connected to stigma (e.g., Link 1987; Rosenfield 1997), and employ specific strategies to protect themselves from expected rejection and discrimination (e.g., Link et al. 1991; Herman 1993; Reidy 1993). Most of these studies have been confined to specific groups or locations; for instance, the largest of these studies (Campbell and Schraiber 1989) involved 331 consumer respondents in California. Others involved members of a Staten Island patient support group (Freedom From Fear 1991), former hospital patients from Southern Ontario, Canada (Herman 1993), and patients from New York City hospitals (Link 1987). In addition, these studies focused on general impressions and expectations of stigma rather than on specific experiences (e.g., Mansouri and Dowell 1989; Freedom From Fear 1991).

In part, the limited number of studies seeking input from mental health consumers may be due, first, to the belief that one can accurately infer from the apparent attitudes of the public what must be the experience of those with mental illnesses; or, second, to the desire for a more controlled (experimental or laboratory) methodology through which to gather data. Omission of consumer perspectives may be due, as well, to a desire not to intrude into the lives of people already sufficiently burdened and to a belief that those whose disorders often impair their perceptions and cognitions may not be able to accurately describe their experiences. However, the neglect of firsthand reports may also be simply an extension of the general neglect of consumer input in all mental health efforts, including research—a neglect that may itself be a reflection of stigma and of devaluation of those with psychiatric disorders.

Whatever the causes, self-report and experimental analogs are no substitute for information about real-life experiences. To truly understand and appreciate what stigma is and how it affects people with mental illnesses,

we have to hear from the ones who face that stigma on a daily basis. They can best inform us—from their own personal experiences and in their own words—what stigma is, what it does, and how it is conveyed.

In addition, the concept of empowerment that is growing in importance in discussions of treatment of mental illness demands that mental health consumers be included in research about their lives. Rapp and colleagues (1993), for example, have noted that "one of the reasons for the dominance of person-blaming interventions and research is that the people [whom clinicians] seek to help have not been judged to be important informants" (p. 729). The idea that listening to mental health consumers and providing opportunities for them to tell their unique stories are important strategies of empowerment and self-esteem enhancement has been echoed by others as well (e.g., Campbell and Shraiber 1989; Rappaport 1995; Corrigan and Garman 1997).

The current study was undertaken, therefore, to expand knowledge of mental illness stigma through a large-scale, nationwide inquiry about the experiences of persons with diagnosed psychiatric disorders, and, in so doing, to empower consumers with the opportunity to describe what life has been like for them.

Methodology

Consumer experience survey: The first part of the study involved the distribution of a survey concerning specific stigma and discrimination experiences. Identification of commonly reported stigma experiences through examination of first-person accounts of mental illness, such as those appearing regularly in the *Schizophrenia Bulletin* and the *Journal of the California Alliance for the Mentally Ill,* led to an initial selection of experiences to include in the survey. In addition, input from a consumer member of the research team and from representatives of the National Alliance for the Mentally Ill (NAMI) was obtained. Finally, we sought feedback from members of NAMI's Consumer Council on both content and wording of a pilot instrument and used that feedback to develop a final survey form.

The final survey had three main sections. The "Stigma" section included nine questions about people's interpersonal experiences as "consumers." Questions addressed such topics as specific treatment by others (e.g., being shunned or rejected), negative things seen or heard about mental illness (e.g., in mass media), and fears and behaviors related to disclosure of status as consumers. Respondents were asked to rate the extent of each experience on a 5-point scale from "never" to "very often."

The "Discrimination" section presented 12 items intended to explore the extent to which consumers had

experienced discrimination in such activities as renting an apartment, getting a job, volunteering, and obtaining a license. It also included items related to treatment in legal and law enforcement contexts, as well as an item concerning avoidance of disclosure of consumer status on written applications. Again, items were rated on a 5-point scale of frequency of occurrence from "never" to "very often."

The third section requested demographic and diagnostic information—age, race, marital status, employment, diagnosis, living situation, and hospitalization history. In addition, respondents were encouraged to elaborate on their ratings and write in additional information if they wished.

Survey participants were sought from three main sources. First of all, the survey was published in the May/June 1996 issue of *The Advocate,* the NAMI newsletter (Wahl 1996). Second, each of the 30 members of NAMI's Consumer Council was given packets of questionnaires to distribute to consumers in his or her home location. Third, the survey was posted on the NAMI Internet site, so individuals could complete and return the questionnaire electronically. Completed surveys also came from other, unplanned sources. For example, people sometimes called to request copies of the questionnaire to distribute at the mental health facility where they worked. In all cases, participants had the option of responding anonymously.

Interviews. One hundred respondents to the written survey were selected for interviews through use of a random number table and a series of decision steps intended to ensure that interviewees were reasonably representative of the larger survey sample (e.g., taking only 10 persons from each consecutive group of 100 respondents). Interviews were conducted by telephone, tape-recorded, and later transcribed and coded. Interviewees were requested, first of all, to describe one or more specific experiences that they had rated as occurring often or very often. Further queries involved what the person's behavioral and emotional reactions had been, how the experiences had affected his or her life, and what strategies had been useful in dealing with stigma. Finally, interviewees were asked for their ideas about how stigma might be reduced and what one message they would like to give people about mental illness. Interviews were conducted by trained doctoral students in clinical psychology and lasted between 25 and 60 minutes.

Survey Results

Participants. Altogether, 1,301 completed questionnaires were received between June 1 and November 1, 1996. As shown in table 1, substantial numbers of respon-

Table 1. Demographic characteristics of survey respondents and interviewees

Characteristic	Survey respondents (n = 1,301)	Interviewees (n = 100)
Geographical source		
States represented	49	43
No. of ZIP Codes	737	98
Distribution source, %		
NAMI *Advocate*	67	74
Consumer Council	20	17
Internet	10	9
Other	4	0
Age, years		
Range	12^1–94	22–72
Mean	41.9	42.7
Sex, %		
Females	56	71
Males	40	29
Unknown	5	0
Marital status, %		
Single, never married	43	31
Married	26	30
Divorced	23	36
Widowed	3	2
Race, %		
Caucasian	80	84
African-American	10	9
Hispanic	1	0
Asian	0.5	0
Other	5	3
Educational level, %		
Did not complete high school	13	2
Completed high school	17	11
Attended, but did not complete, college	27	33
Completed college	22	30
Graduate/professional degree	17	24
Employment status, %		
Never employed	3	1
Not employed, but worked previously	47	55
Employed part-time	20	22
Employed full-time	19	21
Current living situation, %		
Independent living in home or apartment	61	77
Living with parents/other family members	17	19
Semi-independent living in supervised home/apartment	12	2

Table 1. Demographic characteristics of survey respondents and interviewees—*Continued*

Characteristic	Survey Respondents (*n* = 1,301)	Interviewees (*n* = 100)
Currently under hospital care	1	0
No current residence	0.3	1
Other	2	1
Diagnosis, %		
Bipolar disorder	25	28
Schizophrenia	19	17
Major depression	15	16
Schizoaffective disorder	0.5	3
Multiple diagnoses	14	29
Other	5	4
Age at first diagnosis, years		
Range	0^2–75	6–55
Mean	25.7	25.5
Mode	18	20
Number of hospitalizations, %		
Never hospitalized	15	14
1–5 times	43	44
6–20 times	24	35
21–30 times	3	2
30+ times	2	3
Range	0–98	0–98
Mean	5.9	7.2
Indicated a willingness to be interviewed, %	61	—

Note.—Not all respondents answered all questions. Thus, percentages may not add to 100.

[1] Only two respondents were under age 18. Although their young ages (12 and 13) may raise questions about the accuracy of their responses, the author felt it was important to include everyone who shared experiences through the survey.

[2] A zero age at first diagnosis indicates that respondents said they had been diagnosed within the first year of their lives; four made such a claim.

dents came from each of our distribution sources, with the greatest number (67%) from the NAMI newsletter. Responses were received from 49 states plus Canada and Ireland representing more than 700 ZIP code areas.

Respondents ranged in age from 12 to 94, with an average age of 42. Approximately 40 percent of those responding to the survey were male and 56 percent female. Most were single, that is, either never married (43%), divorced (23%), or widowed (3%); only about one in four (26%) were currently married. The respondent sample was predominantly Caucasian (80%), and they tended to have at least some college education (66%): 39 percent had completed college and 17 percent had earned graduate or professional degrees. The sample also

included people who had not completed (13%) or had not gone beyond (17%) high school.

Nearly half the respondents were not currently working, although they had worked previously (47%). More than one in three (39%) were working either full-time or part-time at the time of the survey. Most respondents (73%) characterized themselves as living independently or semi-independently (e.g., in supported community housing); very few respondents were currently hospitalized (1%) or homeless (0.3%).

Respondents presented a diverse clinical picture as well. The most frequent single diagnosis was bipolar disorder (25%), with schizophrenia (19%) and major depression (15%) also common. The modal age at which respondents were first diagnosed was 18. The vast majority of respondents (72%) had been hospitalized at least once, with a mean of six hospitalizations. The range was substantial, however: 15 percent reported never having been hospitalized, but 2 percent indicated they had experienced more than 30 hospitalizations.

Stigma Experiences. The most commonly reported experiences involved witnessing stigmatizing comments or depictions of mental illness (see table 2). Almost 80 percent of survey respondents indicated that they had overheard people making hurtful or offensive comments about mental illness; half reported noticing these often or very often. (Note: Throughout the article, only events that occurred at least sometimes are considered to have a frequency worth noting.) Seventy-seven percent reported encountering hurtful or offensive media portrayals of mental illness at least sometimes; almost half (47%) indicated this occurred often or very often.

More direct experiences of stigma were also reported. Seven of 10 respondents noted they had at least sometimes been treated as less competent by others once their illness was known; such treatment occurred often or very often to more than one-third (36%). More than one quarter of the respondents (27%) found themselves often or very often being advised to lower their expectations in life; for example, they were counseled to reconcile themselves to jobs well below their level of education, intellect, and training.

More than half of those responding to the survey (60%) reported that they had had the experience of sometimes being shunned or avoided. For more than one in four (26%), such rejection was frequent. Less than half (47%) were able to say that friends who learned they were consumers had often or very often been understanding and supportive; one in six (16%) reported receiving such support seldom or never.

Not surprisingly, given these experiences, the majority of respondents (74%) indicated that they had some-

Table 2. Responses to survey stigma items (n = 1,301)

Item	Never	Seldom	Sometimes	Often	Very often
I have worried that others will view me unfavorably because I am a consumer.	137 (11%)	128 (10%)	296 (23%)	316 (24%)	401 (31%)
I have been in situations where I have heard others say unfavorable or offensive things about consumers and their illnesses.	125 (10%)	146 (11%)	369 (28%)	346 (27%)	302 (23%)
I have seen or read things in the mass media (e.g., television, movies, books) about consumers and their illnesses that I find hurtful or offensive.	133 (10%)	149 (12%)	384 (30%)	313 (24%)	303 (23%)
I have avoided telling others outside my immediate family that I am a consumer.	177 (14%)	144 (11%)	357 (27%)	272 (21%)	336 (26%)
I have been treated as less competent by others when they learned I am a consumer.	146 (11%)	204 (16%)	446 (34%)	265 (20%)	207 (16%)
I have been shunned or avoided when it was revealed that I am a consumer.	235 (18%)	257 (20%)	441 (34%)	224 (17%)	118 (9%)
I have been advised to lower my expectations in life because I am a consumer.	305 (23%)	238 (18%)	376 (29%)	214 (16%)	143 (11%)
I have been treated fairly by others who know I am a consumer.	48 (4%)	149 (12%)	485 (37%)	413 (32%)	184 (14%)
Friends who learned I am a consumer have been supportive and understanding.	62 (5%)	145 (11%)	462 (36%)	263 (28%)	244 (19%)

Note.—Not all respondents answered all questions. Thus, numbers do not sum to 1,301 and percentages do not total 100.

times, often, or very often avoided telling others outside their immediate families about their mental illnesses. Avoidance of disclosure, however, appeared to provide only some relief from stigma: fear of discovery remained. Fewer than one in four (21%) were able to say that they seldom or never worried that others would view them unfavorably if their status as a mental health consumer were disclosed; more than half (55%) said they worried about this often or very often.

Discrimination Experiences. There were few reports of actual discrimination; the majority of respondents reported that they had seldom or never been turned down for a job, excluded from volunteering, or denied housing or education on the basis of their status as a mental health consumer (see table 3). However, the lower numbers of consumers reporting these experiences may be due, in part, to consumers not being in situations where these types of discrimination could occur. Approximately 20 percent indicated that one or more of the survey's discrimination items were "not applicable" to them; handwritten comments conveyed that they had been employed only through mental health programs, lived with parents, had not applied for volunteer positions, had never been

involved with the police or the courts, and so on. In addition, 70 percent of those responding reported that they had sometimes, often, or very often avoided disclosure of their mental illnesses on applications for jobs, licenses, or housing and thus may have been able to avoid possible discrimination. Furthermore, about 8 percent of respondents annotated their responses to explain that they had not disclosed or that they had even lied in one or more of the specific situations included in the survey.

Discrimination was far from absent, however, despite the above limiting factors. Approximately one in three consumers (32%) reported that they had been turned down for a job for which they were qualified after their mental health consumer status was revealed. Even when successful in getting a job, some consumers found the work environment unfriendly, as evidenced by the more than one-fourth (28%) of responding individuals who indicated that coworkers and supervisors were seldom or never supportive and accommodating when they learned about the respondent's mental illness.

Some consumers found that even their attempts to contribute on a volunteer basis were stymied. More than one in every five consumers indicated that they at least sometimes had experienced trying to volunteer and were

Table 3. Responses to survey discrimination items (*n* = 1,301)

Item	Never	Seldom	Sometimes	Often	Very often
I have avoided indicating on written applications (for jobs, licenses, housing, school, etc.) that I am a consumer for fear that information will be used against me.	239 (18%)	86 (7%)	196 (15%)	229 (18%)	485 (37%)
I have been treated with kindness and sympathy by law enforcement officers when they learned that I am a consumer.	353 (27%)	150 (12%)	292 (22%)	168 (13%)	113 (9%)
Coworkers or supervisors at work were supportive and accommodating when they learned I am a consumer.	184 (14%)	187 (14%)	365 (28%)	268 (21%)	152 (12%)
I have been turned down for a job for which I was qualified when it was revealed that I am a consumer.	605 (47%)	155 (12%)	217 (17%)	131 (10%)	64 (5%)
I have been denied mental health treatment because my heath insurance was insufficient for me to pay the cost of treatment.	664 (51%)	155 (12%)	196 (15%)	110 (9%)	102 (8%)
I have been turned down for health insurance coverage on the basis of my mental health treatment history.	697 (54%)	103 (8%)	152 (12%)	87 (7%)	136 (11%)
I have been excluded from volunteer or social activities outside the mental health field when it was known that I was a consumer.	690 (53%)	188 (15%)	204 (16%)	75 (6%)	47 (4%)
I have been excluded from volunteer or other activities within the mental health field when it was known that I was a consumer.	776 (60%)	167 (13%)	162 (13%)	57 (4%)	35 (3%)
I have had the fact that I am a consumer used against me in legal proceedings (such as child custody or divorce disputes).	831 (64%)	81 (6%)	114 (9%)	68 (5%)	71 (6%)
I have had difficulty renting an apartment or finding other housing when my status as a consumer was known.	784 (60%)	135 (10%)	150 (12%)	57 (4%)	40 (3%)
I have been denied educational opportunities (for example, acceptance into schools for education programs) when it was revealed that I am a consumer.	858 (66%)	129 (10%)	107 (8%)	49 (4%)	32 (3%)
I have been denied a passport, driver's license, or other kinds of permits when I revealed that I am a consumer.	955 (73%)	89 (7%)	78 (6%)	33 (3%)	22 (2%)

Note.—Not all respondents answered all questions. Thus, numbers do not sum to 1,301 and percentages do not total 100.

turned down because of their illness. Moreover, this was true for volunteering both within (20%) and outside (26%) the mental health field.

Discrimination in obtaining insurance was an issue indicated in consumer responses, as well. Three out of 10 reported that they had been turned down for health insurance, often by numerous carriers, because their mental illness represented a "pre-existing condition." About one-third (32%) also indicated that they had sometimes, often, or very often been denied treatment because their health insurance was insufficient to pay the cost of such treatment.

Interview Results

Interview Respondents. The 100 interviewees were similar to the overall sample of respondents in many

ways, as shown in table 1. They came from 43 different states and from distribution sources in proportions roughly comparable to the overall sample. Again, bipolar disorder, schizophrenia, and major depression were the most common diagnoses, and as with the overall sample, interviewees were predominantly Caucasian. They were also similar in age (mean 42.7 years vs. 41.9 in the larger sample).

There were some differences, however. Interviewees tended more often to be female, college educated, and living independently than did the overall sample. In addition, interviewees were less likely to have never married but more likely to have been divorced.

Interview Responses. One feature we looked at in interviewees' descriptions of their stigma experiences was the source of stigma. The most commonly cited source (by 46 interviewees) was the general community (see table 4). Interviewees described many different kinds of responses from neighbors and people they encountered on buses or in community groups to which they belonged.

Table 4. Most common interview responses about stigma sources and impact

	Number of interviewees giving response (*n* = 100)
Stigma source	
General community	46
Family	39
Coworkers, colleagues, classmates	36
Mental health caregivers	28
Employers, supervisors	24
Friends	22
Reaction to experiences	
Anger, being offended	33
Hurt	28
Took specific corrective action	21
Sadness, depression	18
Discouragement, disappointment	17
Impact of stigma experiences	
Felt a lasting impact	95
Had lowered self-esteem or self-confidence	57
Became less likely to disclose illness	39
Increased avoidance of social contact	31
Became stronger or more motivated to recover	29
Became more guarded, less trusting	27
Became less likely to make application (for jobs, school, etc.)	21
Experienced an increase in problem emotions	14

Work environments were mentioned often, with 36 interviewees talking about the troubling behavior of coworkers and colleagues and 24 mentioning employers and supervisors. Stigmatizing occurred even with friends, according to 22 interviewees. As one described it: "I had one gal that I worked with and we were pretty close together.... I told her that I had had a nervous breakdown ... and after that, she just kinda, we couldn't do anything together because she would find an excuse."

Relatives were also described as sources of stigma; indeed, they were the second most commonly cited source—by more than one-third (39) of the interviewees. Some spoke of being treated as less competent, as reflected in parental overconcern. Said one person: "They start watching you carefully. It's like getting the kid glove treatment and that's irritating." Others reported outright rejection by family. One interviewee noted how his brother, in his presence, denied to others that the two were brothers. Another said, "I have a 27-year-old son who will not speak to me because I am mentally ill."

More than one in four interviewees (28) complained about stigmatizing treatment from the people charged with their care. A recurring complaint again concerned being treated as less competent and being discouraged from setting high goals. Said one consumer: "Frequently psychologists and doctors [seem to believe that] all schizophrenics ... aren't capable and cannot achieve a higher education." Another noted: "I've had case managers hint not to push for the highest accomplishment I can do.... Sometimes it would be nice if they would push for something more than just sitting in chairs all day." Still another interviewee described how the doctor who first diagnosed her bipolar disorder told her that "people with your problem will have a very low level type of life."

In both interviews and remarks written on survey questionnaires, respondents also gave examples of disparaging remarks made by mental health caregivers. One respondent, for instance, reported: "I have worked at [a psychiatric facility]. As with many other facilities in which I have worked, the patients are spoken about with disrespect, sometimes mocked, and often spoken to in shaming ways." Yet another commented similarly on her medical school experience: "The treatment of psych patients in all rotations was awful. They would laugh at them, poke fun at them on rounds, disbelieve any physical complaint they had."

Interviewee responses to questions about their reactions to stigma experiences revealed a variety of ways that such experiences affect consumers. The most commonly reported emotional reaction to stigma experiences was anger, described by 33 interviewees (see table 4). Hurt (28), sadness (18), and discouragement (17) were also reported.

Moreover, stigma experiences, according to interviewees, had a variety of lasting effects (see table 4). In fact, when asked, 95 of the 100 interviewees asserted that there had been long-term consequences. More than half (57) talked about lowered self-esteem and loss of confidence in themselves. They also noted how their experiences had made them less likely to disclose information about their disorders (39), more likely to avoid social contact (31), and less likely to apply for job or educational opportunities (21). In addition, some interviewees described lasting effects on their feelings about and expectations of others, indicating that their experiences had contributed to their being less trusting of others, more guarded, and more sensitive to slight (27); some (14) reported that their stigma experiences had also contributed to the persistence of symptomatic emotions such as anxiety and depression.

There was some good news in what consumers reported about their reactions, as well. About one in five (21), for instance, indicated that they had been able to take some corrective action rather than just react emotionally: They spoke up and attempted to educate people who made disparaging or incorrect statements about mental illness, they filed appeals when they perceived discrimination, and they persisted in attempting to obtain employment or insurance. Some interviewees, furthermore, described being able to turn their negative encounters into positives for themselves, indicating that these encounters strengthened them, made them more resolved to recover, or both (29).

Interviewees also recommended a variety of strategies for coping with stigma (table 5). The most commonly cited coping strategy (by 44 interviewees) involved advocacy; these consumers found that involvement in organized efforts to educate people about mental illness and to change attitudes helped them to move beyond their immediate negative reactions to stigmatizing experiences. Similarly, some (18) reported that immediate direct confrontation of stigma was empowering and self-enhancing. Limiting disclosure was cited as a strategy as well: 17 interviewees stated that they were careful not to reveal their status as a mental health consumer to anyone, and another 13 used selective disclosure—that is, only to family, close friends, or other consumers. Still others found external support to be helpful in dealing with their stigma experiences; in particular, involvement with other consumers, with whom they could feel accepted and understood, was cited as useful by 16 interviewees.

At the end of the interview, each interviewee was asked for his or her advice about reducing stigma and for a statement about mental illness that he or she would like others to hear. Responses are summarized in table 5. The anti-stigma strategy cited most often was public education about mental illness. Two-thirds (66) of the interviewees

Table 5. Most common interview responses about strategies and messages

	Number of interviewees giving response (*n* = 100)
Coping strategy used	
Advocacy	44
Confrontation, challenge	18
Avoidance, withdrawal, concealment	17
Involvement with other consumers	16
Selective disclosure	13
Recommended anti-stigma strategies and messages to others	
Public education about mental illness is needed ·	66
People need to be more understanding	39
Mental illness could happen to anyone	28
Mental illness should be treated the same as physical illness	19
People with mental illness need to be given a chance	17

indicated that people in general—and mental health caregivers in particular—needed to be better informed about mental illness for stigma to be reduced.

In terms of what consumers would like others to know, the most common—and most impassioned—message was a plea for understanding and acceptance, offered by 39 interviewees. Said one person: "Try to be understanding and compassionate. Whenever you hear that somebody's got a mental illness, don't act like they've died or like they're worthless or they're no good anymore, they're ruined.... Esteem them as valuable human beings." Frequently this message was in the form of a request not to be prejudged or stereotyped, but treated as unique and valued individuals. "Don't judge me until you've walked a mile in my shoes" was a theme repeated numerous times. Still other forms of this message included the following: "Think about it if it was you in that situation, how would you feel if you were being treated the way you are treating people in that situation." "Don't take the preconceived notions.... You can't just take the most severe form of mental illness and say that that's the way it is for everybody."

Requests for understanding were sometimes couched in terms of reminders to others that persons with mental illnesses are people like themselves and are individuals, not disorders: "People with mental illnesses, at some point, in some place, are just like everybody else. We got the same wishes and hopes and dreams and we have the

same feelings.... I'm a person, not a disease." "Don't judge a person by their sickness. Judge them by who they are underneath." "I am more than a diagnosis. I am a whole person and I deserve to be treated like a whole person."

Interviewees also wanted to remind others that mental illness could affect their lives as well—often another way of requesting empathy. Twenty-eight interviewees emphasized that "mental illness can happen to anyone." One pointedly advised: "Please try to develop some tolerance and patience because it could be you tomorrow."

Another message was that mental disorders are illnesses like physical illnesses, sometimes including the assertion that "mental illnesses are brain disorders." The fact was used also to underscore the message that persons with mental illnesses are no different from other people with physical illnesses and to remind others that mental illness is not a character or motivational weakness. "Try to understand," said one consumer, "that it's not a matter of willpower, that it can't be mind over matter, that there's as much of a biological basis for it as there is in any other illness."

Discussion

How one interprets these results depends in part upon one's degree of optimism, tolerance, and expectations. It is possible, for example, to look at these consumers' reports as encouraging. Fewer consumers reported being shunned often or very often (26%) than reported seldom or never having had such an experience (38%). A majority reported that they had seldom or never been discriminated against in obtaining jobs or housing. Only one in six said that they had seldom or never been treated fairly by others who knew they were a consumer. That so many consumers seem to have been spared many of these stigma experiences may be seen as a positive result.

On the other hand, when one in four, or even one in six, people experience painful and demeaning events like the ones consumers reported, that may be far too many. To the extent that the respondents in this study sample are similar to the much larger population of mental health consumers, results suggest that millions of people with mental illnesses may still find themselves shunned, avoided, and treated as less competent; may have witnessed themselves being the object of humor, intolerance, and insensitivity; and may have been discriminated against in employment, in insurance, and in volunteer settings. Moreover, their experiences of stigma have not been just at the hands of strangers or in impersonal situations; friends, family members, church congregations, and even mental health caregivers reportedly have contributed as well. Looked at in this way, stigma and discrimination

against those with mental illnesses remain substantial problems.

Results indicate, furthermore, that the experience of "indirect" stigma—negative remarks and media depictions of mental illness that are not directed toward any particular individual or that do not directly express opinions about persons with psychiatric disorders—is the most common. The sources of such comments and depictions probably do not consider that their audiences might include consumers who could be hurt by those remarks. Yet consumers are in many, if not most, of those audiences; and results suggest that they are sensitive to such remarks, which serve as constant reminders of the low esteem in which they are held.

Another result that points to communications that people may not be aware are stigmatizing is the degree to which consumers were sensitive to advice about lowering their expectations in life; more than half said this had occurred at least sometimes. Clinicians and families often feel they are doing consumers a service by helping them to take what seems to be a more realistic view of their situation and to steer consumers away from challenges that may be too stressful and risk relapse. Consumers in our survey, however, experienced such advice differently. Written and interview comments suggest that they felt patronized, devalued, and demoralized. As the increasing success of consumers (often through consumer-run programs) is demonstrating, assumptions about the limited potential of people with severe mental illnesses may indeed reflect negative and inaccurate, though lingering, stereotypes of incompetence and limited recovery potential. Consumers are increasingly rejecting these stereotypes as offensive and harmful (e.g., see Deegan 1990, 1994). While unrealistic ambitions can, at times, be a problem for consumers and guidance toward more realistic goals or slower steps a therapeutic contribution, consumer responses to the survey suggest that families and clinicians need to be aware of the problematic ways consumers may experience such guidance and of the possibility that they are indeed underestimating the potential of the consumer.

Consumers' responses, moreover, show that the stigma experiences described can do harm (although, again, the optimist may be pleased that such harm was not more widely reported). Stigma experiences have caused hurt, anger, discouragement, and lasting damage to self-esteem. They have led many consumers to conceal their psychiatric histories from others, to withhold information on applications for jobs and licenses, and then to be burdened with chronic fear of disclosure in addition to the pain and stress of their illnesses. Experiences have led many consumers to maintain a secrecy that not only is uncomfortable but also may contribute to the very symp-

toms—anxiety, depression, paranoia—from which they are struggling to recover. Moreover, fears about stigma appear to result in reluctance to apply for jobs, education, or insurance or even to seek treatment. In making productive work less available, in limiting treatment resources (e.g., insurance) and discouraging treatment-seeking, in contributing to social isolation, and in generating nagging fears about disclosure and community rejection, stigma experiences have produced conditions antithetical to the goals of recovery.

Another possibly troubling finding from this study is that mental health caregivers were implicated repeatedly (e.g., by 28 of the 100 interviewees) as contributors to stigma, not just through their discouraging advice but also their disparaging remarks and rejecting behavior. And when those whom consumers especially look to for understanding and support deliver instead ridicule and disrespect, the consequences must be more devastating than when discouragement comes from strangers. That consumers could point to numerous instances in which those designated as "helpers" have shown stigmatizing behavior strongly suggests that caregivers need to examine and modify their own attitudes and actions toward people with psychiatric disorders. The messages of consumers—that they desire greater empathic understanding and wish not to be judged by their labels—would seem to be aimed particularly at mental health caregivers, for whom empathic and nonjudgmental behavior is presumably central to their professional roles.

Among the more clearly positive results of this survey is information about the ways consumers can and do deal with stigma. Involvement in advocacy and speaking out are self-enhancing, and the courage and effectiveness shown by such participation help to restore self-esteem damaged by stigma. The perceived helpfulness of talking with and being understood by other consumers supports the value of self-help and consumer support groups. There were indications also that the message of NAMI's current Campaign to End Discrimination—that "mental illnesses are brain disorders" (National Alliance for the Mentally Ill 1996)—has helped some consumers resist stigmatizing attitudes that imply that moral and character flaws underlie disturbed behavior.

Cautions and Limitations. The major caution in considering these results concerns the nature of participants. While respondents were quite diverse, in many ways they are not fully representative of the population of people with psychiatric disorders. First of all, most respondents had diagnoses of severe mental illnesses. Whether or not similar stigmatization occurs for those with less severe diagnoses or for those who seek outpatient psychiatric treatment for adjustment and relationship difficulties is not

addressed by these data. A broader sample that includes people with less severe disorders would be useful in determining the extent to which any diagnosis or psychiatric treatment would lead to similar stigma experiences.

Our sample also was a relatively high-functioning one, given the nature of the disorders represented. Those whose disorders were not yet stabilized (e.g., those in hospitals), who were not recovered enough to obtain and respond to our survey, who were not reached through our survey distribution sources (e.g., those not associated with NAMI or with treatment programs or who are homeless), and those who have not yet accepted their illnesses enough to talk about them would not have been included in our results.

Furthermore, all of our distribution sources were NAMI-connected, and some of our findings may have been influenced by that connection. Given that we have reached those associated with an advocacy group, it is not surprising that many saw advocacy and public education as important tools for fighting stigma, nor is it surprising that they espoused NAMI's assertion of mental illness as a brain disorder as an important message to the community. While this should not change the fact that advocacy and conceptualization of mental illnesses as similar to physical illnesses were helpful to those with whom we spoke, it would be inappropriate to conclude that those strategies are being used by most consumers.

Respondents were also self-selected. They chose to take the time to return surveys and to speak with us. It is certainly possible that these individuals were particularly sensitive to stigma or particularly motivated to contribute to our study because they had had troubling stigma experiences, thus skewing our results toward greater stigma. At the same time, it could be argued that those with schizophrenia—constituting about half the population of psychiatric hospitals—were underrepresented in a sample in which the vast majority had been hospitalized and that, given schizophrenia's reputation as the most highly stigmatized psychiatric disorder, the underrepresentation of people with schizophrenia skewed results toward less stigma. Again, then, we cannot be certain that current results are indicative of the overall level of stigma experienced by the *typical* mental health consumer.

A final caution concerns the identified sources of stigma. That families and mental health caregivers were many times described as sources of stigma may reflect the fact that those are the people with whom consumers are in most contact. Families and caregivers may be no more prone to stigmatizing than other groups, but they are the ones consumers have the greatest opportunity to observe stigmatizing. It is also possible that stigmatizing from families and caregivers, to whom consumers are more emotionally attached, may make a greater, more memo-

rable impact, thus making it more likely that stigma experiences involving them would be recalled in the survey.

These cautions, however, do not negate the conclusion that many consumers—from different circumstances, from different parts of the country, with different diagnoses—have experienced stigma and discrimination in their lives and have been adversely affected by it. These results still may be seen as a call for continued attention to stigma as a central and powerful experience of mental illness and an alert that even those who care for and about consumers can contribute. The clear messages of consumers—to give them empathic understanding and to not judge them by their labels—are ones to be heeded by all.

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