From Stigma To Discrimination:
An Analysis of Community Efforts To Reduce
the Negative Consequences of Having a
Psychiatric Disorder and Label

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Abstract

Discrimination related to psychiatric disorders and people diagnosed with them is receiving increased interest and attention from researchers, policy makers, and the general public. There are diverse views about how best to alter and reduce what all parties agree are personally painful, socially wasteful, and morally inexcusable practices that surround people with psychiatric disorders. We report the results of a first step national survey of noteworthy on-the-ground efforts to reduce the negative consequences of having a psychiatric disorder and label. The sample consists of nontraditional, innovative local efforts along with well-known programs. Nominations of exemplary antistigma and antidiscrimination efforts were solicited from a national data base developed for this project. Next, an expert consensus panel selected 36 exemplary programs from among 102 nominations. A descriptive analysis and summary of the shared qualities of exemplary programs are provided.

Keywords: Discrimination, stigma, psychiatric disorders, community-based programs.


When I am isolated and ignored because of my psychiatric disability, when I am distinguished unjustly and my rights disregarded, that is prejudice; that is discrimination. Calling it by a word [stigma] only used for mental illness allows people to separate the wrong from other social injustices. Calling it by a word only used for mental illness disallows us the political and social change leverage of language everyone understands . . . to remove real shame it must be named correctly. We must expose shunning and shaming as the prejudice and discrimination that it is. (Caras 2000)

Efforts to counter and alter noxious views and treatment of people diagnosed with psychiatric disorders are long-standing and widespread, but comparatively little is known about their conceptual and operational elements, and their range, impact, and locales. Here we report the results of a first step national survey of noteworthy on-the-ground efforts to reduce the negative consequences of having a psychiatric disorder and label.

We sampled nontraditional, innovative local efforts along with well-known programs to develop an informed grasp of the conceptual and operational elements of activities that are recognized as having a positive impact at the local level. It is important to emphasize that this study was neither designed nor intended to assess the effectiveness or success of individual programs or activities in the same manner as much prior controlled, experimental research on stigma. Instead, we relied deliberately on the judgments of the broader mental health and psychiatric services community to establish the noteworthiness and impact of the programs. The naturalistic design of the study permits us a unique sample of what strategies and content are viewed as effective by those with the most direct involvement in community efforts to reduce stigma and discrimination. This preliminary survey cannot

1 Over half (55%) of the programs nominated indicated that they collected evaluations or feedback from their audience. We did not collect or analyze this information, but in further work this would be a valuable exercise.

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address in any definitive way important questions about “what works” to reduce discrimination and stigma. However, we do provide initial reconnaissance regarding the types of existing programs, their constituents’ assessments of the programs’ impact, and their overall conceptual and operational elements.

Background

Historical, Political, and Conceptual. Antidiscrimination and antistigma programs, particularly the community-based efforts that are the focus of this study, are, de facto, advocacy activities that exist within and because of social, political, and ideological contexts. This is research about activism and advocacy catalyzed by both structural injustices and deprivations of civil rights, and intensely personal experiences of exclusion and shame. It is therefore essential to take account of these factors and forces in any analysis.

Discrimination related to psychiatric disorders and people diagnosed with them is enjoying a period of renewed interest and attention from researchers, policy makers, and the general public. The 1999 Surgeon General’s Report on Mental Health (U.S. DHHS 1999) and the President’s New Freedom Commission on Mental Health (2003) highlighted what many who experience psychiatric disorders and symptoms, and those who live and work with these individuals, needed no such inquiries to establish (Perlick et al. 2001; Dickerson et al. 2002; Corrigan et al. 2003b). The despair, anger, and isolation that result from various forms of exclusion, devaluation, discrimination, and humiliation related to having a diagnosis of psychiatric disorder are persistent and debilitating in and of themselves (Angell et al., in press). Two publicly funded national efforts, the Elimination of Barriers Initiative, and a Resource Center to Address Discrimination and Stigma, are under way, focused on stigma and discrimination directed at and experienced by people with psychiatric disorders. The diversity and passions of these new and extant antistigma activities reflect changes in language; changes in local, State, and national politics, policy, and treatment; and the usually creative tensions among the various constituents concerned with the well-being, treatment, and experiences of people with psychiatric disorders.

The basic fault lines encompass competing versions of the nature, causes, and treatments for psychiatric disorders; differing positions on who speaks for whom; disputes about authority based on authenticity and experience versus authority based on profession or technical expertise; the role of medications in promoting or impeding recovery, and whether medication should be the centerpiece of mental health services; disagreements about the positive outcomes or the unintended consequences of medicalizing and biologizing psychiatric disorders; and the use or prohibition of forced confinement and treatment (see also Crossley and Crossley 2001). While these are not new debates (Clausen 1981; Link and Phelan 2001a, 2001b), they have increased in volume and velocity during the current revival of concern. Many of these points of divergence surface inevitably in efforts to reduce stigma given the wide array of people and perspectives engaged, and provide the complex context for the current investigation.

In view of this context, it is tempting to hyphenate, combine terms by various means, and concoct unwieldy phraseology to ensure accuracy and to steer clear of intellectual and political potholes. In the end, clarity, accessibility, and accuracy in prose take precedence, and so we use terminology that serves those ends. The subject matter of this study, the advocacy and activism of many who call themselves by various designations, leads us to adopt “consumer survivor” as the most accurate and inclusive terminology. Recognizing the longstanding and recurrent debates about the accuracy and validity of psychiatric diagnoses, we use various versions of the phrase “people who have and have a diagnosis of psychiatric disorders.”

Prior Research. We are not aware of previous attempts to identify, describe, and analyze systematically the no-doubt-hundreds of ongoing on-the-ground programs nationally that address psychiatric stigma. The National Stigma Clearinghouse and advocacy organizations such as Human Rights Watch (2003) and the National Alliance for the Mentally Ill (NAMI) are repositories for relevant reports, links, and contact information but do not have as their mission the analysis of these activities. There is, however, a significant and rapidly growing body of research about the components, mechanisms, and mutability or insensitivity of prejudice, discrimination, and stigma directed at, perceived by, and experienced by peo-

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2In the arena of political activism and advocacy, as well as in scholarly discourse about it, language is carefully scrutinized and infused with power. In 1992, for example, the American Psychological Association Committee on Disability Issues in Psychology released Guidelines for Non-Handicapping Language in APA Journals, for example (www.PsychNET.org). The guidelines describe “problematic” and “preferred” terminology directed at lessening unintentionally stigmatizing language in professional discourse. It is a challenge to write from the center of this contested terrain (Penn and Drummond 2001). In recent years, the debate about preferred and accurate terminology for people who have been diagnosed with psychiatric disorders has been energetic and at times difficult. Torrey’s (1997) editorial in Psychiatric Services challenging the validity of the term “psychiatric survivors” elicited “an all time record” of responses for a single article, according to the journal’s editor (1997, p. 601). The journal published excerpts from 20 of the 70 responses illustrating the range of agreement and disagreement with Torrey’s position.
peple who have and have a diagnosis of psychiatric disorders. Nearly all of these studies have been controlled, constructed quasi-experimental investigations. A recent review of research on efforts to reduce stigma concluded, “One need for future research is for studies to be conducted using naturalistic settings that translate into real-world situations and that are possible to implement as a means of reducing stigma in the general population” (Couture and Penn 2003). This gap in information and understanding motivated and guided this study.

In view of the pragmatic and limited focus of this study, we have limited our review of prior and foundational work. The repeatedly reported finding that the public’s fear of violence by persons with psychiatric disorders provides a salient backdrop (Link et al. 1999; Phelan et al. 2000) but is not foregrounded here. Corrigan and colleagues (2001, 2002, 2003a, 2003b; Corrigan and Penn 1999), and Penn and colleagues (1994, 1999; Penn and Drummond 2001), in their work on stigma reduction, have contributed much of the research that is most directly relevant to this study.

Various approaches to reducing psychiatric stigma have been attempted, primarily through education and promoting contact (Corrigan and Penn 1999). In general, the findings suggest that both approaches are effective in reducing stigma, with contact effects being especially impressive and robust (Kolodziej and Johnson 1996; Corrigan et al. 1999; Couture and Penn 2003). These contact effects appear to be strongest if the participants meet as equals, if they work cooperatively, and if institutional support is present. Unfortunately, unanswered questions and limitations plague work in this area.

Many studies have examined the effects of previous self-reported contact on stigma, rather than how prospective contact changes stigma (e.g., Link and Cullen 1986; Roessler and Salize 1995; Ingamells et al. 1996; Angermeyer and Matschinger 1997; Arikan and Uysal 1999; Holmes et al. 1999; Read and Law 1999). In those studies in which direct contact was measured, the manipulation often took place in the context of contrived laboratory situations (e.g., Desforges et al. 1991; Nosse 1993) or as part of a course and/or training program (e.g., Arkan and Eker 1997; Corrigan et al. 2003b). In addition, the mechanism(s) underlying stigma reduction, as a function of contact, is unknown. In other words, are changes in stigma-related attitudes due to changes at the cognitive level (i.e., recategorizing individuals with mental illness as “us” rather than “them”; Gaertner et al. 1990) or due to dampening of physiological arousal (e.g., habituation; Blascovich et al. 2001)?

Corrigan et al. (2002, 2003a) found that while fear of people with psychiatric disorders is strongly related to anger and avoidance, beliefs about controllability of behavior and responsibility for the condition were not nearly as strongly related to sympathy, pity, or helping behaviors. Attribution theory was a much less robust predictor of their results than a danger appraisal model.

Applying attribution research to community-based stigma reduction may be problematic in that beliefs about cause, controllability, and responsibility exist within complex cultural contexts and biographical experiences that vary widely among respondents rather than in a linear, logical relationship, as the theory asserts (Das 2001). Estroff et al. (1991) reported that many of the persons with serious psychiatric disorders in their study held views about the cause, meaning, and mechanisms of their problems that could be considered contradictory if one had a one-dimensional (e.g., medical, emotional) model of psychiatric disorder. Among the consensus panel for this study, there were similar, widely differing views of the nature and causes of mental illness, and even how to refer to them. One panel member said, “When a program uses medical model language such as ‘stigma of mental illness,’ ‘symptoms,’ ‘chemical imbalance,’ ‘illness like any other illness,’ then they are putting out ONE particular point of view . . . and excluding the many other points of view. The outmoded language that narrows this issue to a medical one excludes many people.”

This view was countered emphatically by another consumer survivor panel member, who said, “The mental health as illness theory works for me. It works for a lot of people that I know. I would love to be able to pretend that I can make a ‘choice’ whether or not to take medicine, without mentioning the consequences of that action. Of course, when (sometimes because of insurance questions) I have been ‘off’ my medications, I definitely remember the consequences. Are there problems to the medications? Well, yes. Do I choose to keep taking them? Well, yes.”

Corrigan (2000) suggests that a shift in attributions, from controllable to uncontrollable, may correspond with a change in feelings, from anger to sympathy, which should augment helping behavior. It is possible that sustained interpersonal contact with people with serious mental illness debunks the myth that their condition is under their control. Thus, more positive interpersonal contact could have beneficial effects in reducing the consumers’ experience of being stigmatized and in improving community members’ attitudes toward individuals with serious mental illness. However, it is unclear whether one, a combination, or any of these mechanisms is important for changing stigmatizing views.

It is as plausible that if people believe that a person with serious mental illness did not cause and cannot control the illness, more fear and distance related to unpredictability will result (Read and Law 1999; Corrigan et al. 2003a). In addition, some people with psychiatric disorders object strongly to the assertion that what they have is only a disease, finding this attribution degrading (Clay
As is clear from the previous discussion, attitudes related to people with psychiatric disorders and stigma among the public and persons with serious mental illness are multidimensional, and an array of informed interventions that recognize and address themselves to this nexus of difference are required in response (Tolomiezenko et al. 2001). Beliefs and understandings about responsibility and controllability in relation to people with psychiatric disorders treat on ambiguous, powerful, and contentious turf. In this volatile and shifting terrain, assumptions about the relationship among cause, control, and responsibility should be subject to investigation rather than assumed.

It would indeed be unfortunate if efforts to reduce discrimination and stigma based on laboratory and controlled research had the unintentional effects of further alienating or humiliating consumer survivors and catalyzing additional negativity among the public. It is unclear and generally unexamined whether and how laboratory-based stigma reduction strategies can be exported to the community. At the same time, we need to consider whether and how stigma reduction approaches that are effective in the community can inform future research in controlled settings. The programs described in this article provide an opportunity to investigate these questions.

Conceptual Model

Figure 1 presents the conceptual and operational elements that were elicited in the study instruments. We derived these elements from prior research on stigma, conceptual analyses of discrimination and stigma, and our experience with both research and implementation of community-based stigma reduction activities.

Because we were investigating on-the-ground programs and activities, we were interested in their philosophical and practical dimensions, and in the performative modes that were used. The conceptual elements consist of presentational styles or approaches (activities), perspectives, and program focus and goals. While there is a dearth of systematic research on these topics, a great deal of information is available from published and unpublished consumer survivor accounts and from national advocacy agencies, national mental health practice organizations, and a variety of other potential sources of information. A LexisNexis search was conducted to identify local or otherwise unknown programs mentioned in the press, as well as more traditional electronic searches of journals and publications related to mental health research and practice. The Web sites of consumer survivor and other disability rights and advocacy groups were also searched. After explaining the nature and goals of the study, the request for nominations sent to all of these sources invited them to identify and describe programs in their locale that were successful, effective, or otherwise worthy of note.

An extensive questionnaire accompanied the request for nominations and constituted the primary data collection instrument for the study. The survey content derived directly from the conceptual model is illustrated in figure 1. Structured checklist questions covered the forms of presentation of the program or activities, the approach or philosophies endorsed, the number and type of participants, the organizational components of the program such as funding and relationship to other groups, the audiences and impact of the program and its duration and frequency of activity, and open-ended queries probed for qualities that the nominator thought were exemplary. There were opportunities for the respondents to make additions to any of the checklist items, but this option was seldom used. The survey was developed specifically for this study and was not subjected to psychometric analysis because of this limited and preliminary use. The near-absence of inquiries and additions from respondents, and the large number of completed surveys, attest, in a limited way, to the face validity of the questionnaire. Respondents could elect to complete an electronic version or provide information over the telephone.

We received 117 responses, and 102 were complete enough to be included in the sample. In an effort to increase the sample, most nonresponders were contacted once, and incomplete nominations were followed up by telephone interviews when possible. The response rate of approximately 17 percent was disappointing. However, in view of the exploratory nature of the study, our limited time frame and resources, and the wide geographic distri-
Figure 1. Conceptual and operational elements of programs that counter discrimination and stigma associated with mental disorder

Conceptual Elements
- Humorous approach
- Pathos approach
- Protest/assertive advocacy approach
- Collaborative approach
- Complementary/alternative medicine approach
- Personal approach
- Focus on healing perspective
- Evidence-based vs. anecdotal (operational/conceptual)
- Alignment with other disabilities
- Disability as a social construct and condition perspective
- Spiritual perspective
- Recovery perspective
- Human rights/discrimination/empowerment perspective
- Alike others vs. different from others
- Focus on specific issue such as forced medications
- Pursuit of tangible outcomes
- Pursuit of personal acceptance
- Political action for systems change focus
- Motivation (for resources)
- Primary focus on educating others
- Partnership in treatment—equity of power in treatment
- Consumer survivor—only ideology
- Collaborative ideology
- One ideology and one label
- Illness/medical ideology
- Multiple ideologies and labels

Operational Elements
- Number of people involved
- Solo practitioner vs. group
- Participants—consumer, professional, advocate, family member
- Presentation mode—speeches, movies, slides, posters, vignettes, audience interaction
- Funding—charge/no charge, source
- Duration
- Autonomy—freestanding or connected to other event/context
- Audience—who
- Amount of activity
- Focus—media, politics/policy, incidents
- Organizational structure and leadership
- Impact

3Heberlein and Baumgartner's (1978) review of response rates to mailed questionnaires found that about 5 percent of the studies reported rates similar to ours. It is quite likely that many of our questionnaires "got lost" within State and local mental health agencies because we had to rely on Web sites and other directories for the names of potential recipients, who were in positions with frequent turnover.
researchers, educators, and consumer survivor activists with a wide range of views and experiences. The panelists were selected by the principal investigator based on their extensive prior experience with discrimination and stigma reduction activities; mental health service provision; research on stigma and mental illness; administration of and consultation with mental health services in many different locales and at different levels of mental health systems; and mental health advocacy and activism. Some of the panelists also had experienced psychiatric disorders firsthand. They represented a geographically, demographically, and ideologically diverse group and were paid for their participation.

Prior to two 4-hour teleconferences, panel members reviewed a description of the study and its conceptual frameworks, background readings on stigma, and all of the nominations. Their primary task was to select the most outstanding from among the programs in the sample. No guidelines were provided to the panel regarding what should constitute an exemplary program, and there were no restrictions on the number of exemplars they could select. Instead, we deliberately sought their views of which programs were exceptional and what conceptual and operational elements contributed to this assessment. This strategy was essential to the consensus process and to the goals of the study. We chose an inductive approach because this was an exploratory study and because we did not want to predetermine or influence one of the major outcomes of the study—that is, the identification of what contributed to the panel’s selections of outstanding discrimination and stigma reduction activities.

The panel’s work was facilitated by the principal investigator, following a structured agenda developed beforehand and agreed to by the group. The first meeting focused on making introductions, setting ground rules, and coming to consensus on basic definitions and principles. At the second meeting, panel members presented their selections for exemplars, having circulated these electronically prior to the discussion. The remainder of the session was devoted to extensive attention to the exemplary qualities of the selected programs and to debate about inclusion of additional programs among the exemplars.

To establish a common understanding of the basis for the programs under review, the panel reviewed and discussed extensively various definitions of stigma. The five-component definition of stigma proposed by Link and Phelan (2001a, pp. 367–368) was agreed upon as the most comprehensive and dynamic. The components are (1) distinguishing and labeling differences, (2) associating human differences with negative attitudes, (3) separating us from them, (4) discriminating and reducing status, and (5) linking stigma to power. This formulation was particularly appealing because of the inclusion of interpersonal and social mechanisms such as differences in power between stigmatizers and their objects. As Link and Phelan observe, “What matters is whose cognitions prevail—whose cognitions carry sufficient clout in social, cultural, economic, and political spheres to lead to important consequences for the group that has been labeled different” (2001a, p. 378). As one panelist explained in more personal terms, “Prejudice and stereotype exist in the mind of the other. They are beliefs, not tangible. Discrimination exists in the actions of the other, and is measured by generally accepted social standards and laws. Stigma exists as the mark on me that I carry, my shame. It doesn’t exist without my shame. If I don’t take on the shame there is no stigma.”

Additional discussion about the experiential and emotional dimensions of being stigmatized led to agreement about the need to include the intrapersonal domain in the assessment of the nominees’ efforts and perspectives. In the words of one panelist, “And shame . . . I don’t know why shame isn’t more addressed, [and as another panelist added], pride. Is it too uncomfortable to speak of, too shameful an emotion to even feel? Whom else would I make uncomfortable if I said, ‘I was ashamed?’”

The panel members also commented on and critiqued the conceptual framework for developing a descriptive and analytic typology of these programs (figure 1) and proposed underlying principles and themes for exemplary activities. With this foundation, the panel reached agreement on 36 exemplary programs. Another 20 nominees were judged to be exemplary by at least one panel member, who had the opportunity to make a case for inclusion as an exemplar to the rest of the group. At the end of discussion for each of these, the entire panel had to agree to include or exclude the program as an exemplar.

The panel discussions were taped and were reviewed repeatedly to construct a preliminary version of the exemplary qualities discussed below. After the teleconferences, all panelists prepared and circulated for comment their views of exemplary qualities in the programs that were selected. Then a synthesized draft of exemplary qualities was circulated to the panel members for additional comment and amendment.

Findings

Despite the wide array of nominations and the diverse backgrounds and perspectives among the panel, there was significant agreement on 5 exemplary programs (5+ votes) and some agreement on 31 others (12 received 2–4 votes, and 19 had 1 vote and survived extensive discussion within the group). Twenty-four States are represented among the 36 exemplary programs selected.
There are substantial similarities in both the conceptual and the operational domains within the entire sample, and between the exemplars and other programs. Because there was prior selection for outstanding qualities by the respondents, we recognize all of the nominated programs as "exemplary," in a sense, but for purposes of clarity refer in this article to the 36 programs selected by the panel as "exemplary" and the remaining programs as "other." Based on the work of the consensus panel, the data base was divided into exemplary and other programs, and simple cross tabulations were conducted to identify any statistically significant differences between the two types of programs. There were none. Where there were differences, these were in large part differences of emphasis. Tables 1 and 2 describe the sample in terms of conceptual and operational elements.

We review and discuss the findings for all the programs and then discuss the qualities of exemplars and the other nominees in light of the consensus panel's process.

Activities

Contact and Education. Public presentations such as individual speakers, training workshops, and speakers bureaus that involve contact between consumer survivors and the public are nearly universal among the sample. Half of the programs involved individuals "telling their stories" or otherwise educating various audiences about psychiatric disorders and the people who live with them. What was somewhat unexpected is the extent to which training, consulting, and presenting at conferences are practiced. This suggests that the programs in the study are targeting their work and that they are increasingly asked and allowed to participate in arenas that even a decade ago would not have seen such inclusion. The trainer, conference presenter, and consultant are in positions of authority and are endowed with expertise. This represents a change in how mental health professionals and consumer survivors interact, and it indicates that there is growing consumer survivor empowerment and impact on mental health providers and practices.

A 1993 study on stigma commissioned by the Community Support Program at the National Institute of Mental Health (now the Center for Mental Health Services [CMHS]) (Reidy 1993, p. 1) concluded, "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." Reidy's findings reflect a growing recognition that some consumer survivors see treatment experiences as significantly debilitating in and of themselves (Wahl 1999; Estroff 2004). Angell et al. (in press) update and add detail to this discussion by categorizing stigmatization by mental health professionals as dehumanization, infantilization, and lowered expectations for improvement. Thus, the focus on training and consultation within mental health systems by antistigma and antidiscrimination programs is a promising approach to this most difficult area.

Historian of psychiatry Roy Porter observes, "It would be silly to blame all this scapegoating on doctors, for beliefs about sickness are not simply matters of pathogens but functions of social tensions too... What is clear from history is that if we are going to take the stigma out of mental illness, we cannot simply leave that task to the doctors" (1998, p. 1050). Training and consultation thus may efficiently address and begin to repair the
Table 2. Sample operational elements (n = 102) — continued

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<td>Political clout</td>
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<td>Participation in advisory capacity</td>
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<td>Previous awards</td>
<td>19.8</td>
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<td>Retraction of articles</td>
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Note.—MH = mental health; NAMI = National Alliance for the Mentally Ill. Items within categories on this table are not mutually exclusive, so the percentages reported do not sum to 100 by category. There are missing values for some items.

reciprocal dynamics between “social tensions” about people diagnosed with psychiatric disorders and the attitudes and approaches to treatment of mental health professionals.

While some research suggests that training has a limited impact on stigma (Shor and Sykes 2002), many of the study respondents had a different view. One consumer-run group reported, “We are seeing concrete change happen as a result of this work [training]—reduction in seclusion and restraint, making stigma training (done by us) part of orientation in community psychiatry programs, etc. The most common comment on the evaluation forms is ‘I had no idea I had these stigmatizing ideas and behaved in stigmatizing ways—until this workshop.’” As one consensus panelist concluded, “Interpersonal contact with individuals who have experienced shame, hearing voices, seeing things, etc., continues to be one of the best practices, when it is in a setting that allows for real exchange.” It is perhaps the combination of contact with equality in status and recognition of expertise that occurs in training, workshops, and conference seminars that accounts for the positive impact on both the audience and the presenters.

The contact hypothesis suggests that factors such as equal status, perceived pleasantness, cooperation, intimacy, and the voluntary nature of contact are all important in changing peoples' attitudes toward stigmatized groups (Desforges et al. 1991; Islam and Hewstone 1993; Kolodziej and Johnson 1996). Contact is more effective when the participants are seen as equals, when contact is intimate (one-on-one), and when people work together in a cooperative rather than competitive manner. It is reasonable to conclude that contact and education work most effectively together, and that the kind and quality of contact are crucial factors in altering stigmatizing views and behaviors. The activities of the programs in the sample demonstrate widespread tacit recognition of this surmise.

Expressions and Transactions. Aside from structured speaking and educational activities, drama and other art/creative expressions are each reported by about 14 per-
PERSPECTIVES AND POSITIONS. The various perspectives and approaches to mental illness evident among the programs (table 1) reflect the wide array of views and ideologies within mental health activism and advocacy, and to a certain extent within the scholarly and practice arenas. Nearly all the programs, around 80 percent, endorsed the view that recovery is possible, that the personal experiences of consumer survivors convey this and other important messages, and that people with psychiatric disorders are different from others but have an equal claim to human rights and to freedom from discrimination. Recovery language and activities were widespread among program descriptions and publications. Along with recovery, the embrace of empowerment and enhanced consumer survivor control, rights, and “voice” are clearly focal points among many groups.

Comparatively few (35%) programs focused on the fact that people with psychiatric disorders are similar to other people, while almost 80 percent subscribed to the “difference from others” perspective. This is worthy of note because normalization has been a prominent strategy in antisigma campaigns since their inception. One of the first mental health–related posters to be circulated nationally, in the early 1900s, reads, “Some people believe that mental illness is a disgrace . . . but SCIENCE teaches, Mental illness is no disgrace. Like physical ills, it requires prompt medical care.” In the same tradition, NAMI disseminated a poster during the 1990s that featured a cross sectional drawing of a head and brain with a caption that declared, “The brain is part of the body. It, TOO, can become ILL. Schizophrenia [and] depressive disorder are no fault brain illnesses” (emphasis in original), and NAMI prefers the term “neurobiological disorder” to mental illness. Alternately, some consumer survivor groups voice a variety of objections to unidimensional or predominantly biological and medical views of psychiatric disorders. From this perspective, some antisigma campaigns may have the unintended consequence of tacit psychiatric labeling that in turn obscures the civil and social rights, and other identities, of consumer survivors.

Medication as a normalizing strategy to reduce stigma has yielded mixed results and has become a contested tactic and perspective among various constituencies within a diverse and vocal mental health activist community (Crossley and Crossley 2001; Corrigan et al. 2003a). Indeed, only slightly over half, or 54.9 percent, of the sample included medical and illness-related paradigms in their approaches to stigma. Spirituality as an approach to psychiatric disorder and stigma was endorsed by nearly as many programs (46.1%). In view of the enormous stake and roles that consumer survivors have in the work of stigma and discrimination reduction, these perspectives deserve particular attention.

Over two-thirds of the sample were described as having a collaborative approach to their work (69.6%), a stance further borne out by their report that nearly 60 percent have ongoing connections to other organizations, and 43.4 percent receive some funding from State mental health authorities (table 2). Seeking partnership and equity in power with mental health providers was also widely reported among the sample, consistent with the empowerment values and practices evident in so many programs. Overall, very few programs (4.9%) take a consumer survivors–only approach to their work. It is apparent that empowerment goals and seeking to adjust the balance of power between providers and consumer survivors do not preclude collaboration in efforts to reduce discrimination and stigma.

Finally, the vast majority of the sample (nearly 90%) have in common the goals of educating the public to increase acceptance and understanding of the experiences of people who have and have a diagnosis of psychiatric disorders, and recognition of the direct benefits to participants in their own paths to recovery. Those programs that

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4This is all the more remarkable because we inadvertently undersampled programs that take a decidedly nonmedical, non-illness-oriented approach. We learned in the course of the study that a great many consumer survivor activist and advocacy organizations did not respond to our solicitation because we used the word “stigma” instead of the words “discrimination” and “prejudice.” These organizations practice “inclusion” in the sense that they do not exclude membership by consumer survivors who are comfortable with medical models of psychiatric disorder and who rely on and adhere to medication as a part of treatment. However, in general, as demonstrated amply in their publications and activities (Crossley and Crossley 2001: Angell et al., in press), they do not endorse a medical, biological, or neurochemical view of psychiatric disorder and focus on human and civil rights and discrimination.
indicated a specific issue focus reported also working on empowering consumer survivors by preparing them to be providers or offering them training and education in advocacy, rights, and politics; resources and systems change; and life skills acquisition.

Despite common goals, the programs in the sample demonstrate creativity and imagination in their approaches, and significant variation in their ideologies and principles. The programs use multiple combinations of methods, media, and talents, and an equally eclectic mix of collaborations and connections. One inescapable conclusion from this descriptive analysis is that no single message or approach to reducing discrimination and stigma will have the desired impact or be acceptable to all constituents.

**Operations**

Table 2 summarizes the operational dimensions of the sample and provides a rare profile of organizational frameworks and practices of extant antistigma and antidiscrimination efforts. Most respondents indicated that they worked in groups (77.2%) whose size varied substantially and that their activities were ongoing (87.1%). Solo practitioners, primarily authors and individual speakers, account for slightly less than one-quarter of the nominees. Over half of the programs reported that they had grown since their inception. Undoubtedly, local and global factors have influenced the increase and spread in activity apparent in the sample. Crossley and Crossley (2001, p. 1488) analyze a similar transformation “from personal voices of lone description to increasing collectivization, [and] challenge” in the mental health user movement in the United Kingdom, crediting the transformation to the burgeoning of consumerism in health care in general, and the “new entrepreneurs” of self-help, new psychotherapies, and complementary medicine. The Internet has only accelerated the development of communications and thus communities of people with the most exotic or the most familiar diagnoses, diseases, and differences. Part of the growth evident in the sample is no doubt due to NAMI’s recent introduction of the In Our Own Voice and Breaking the Silence national antistigma campaigns. Nineteen of the nominees were local versions of or national participants in this effort.

In addition to the growth of programs, the duration of those in the sample is noteworthy. About two-thirds of nominees have been in operation for over 2 years, and almost one-quarter have been in existence for over a decade. The survival and success of the nominees may be interrelated, and so this endurance profile may not be generalizable to other antistigma programs. Still, the picture that emerges for this sample is of programs that are funded in large part by State and local mental health authorities (43.4% and 29.0%, respectively) in addition to private donations (53.0%), with connections to State or local government or local mental health agencies (23.5%), other advocacy groups (20.6%), and NAMI (18.9%).

These noteworthy programs display an embeddedness within the community and in collaborative advocacy groups that undoubtedly enhance their endurance, membership, and impact. Over half, 58.0 percent, of the programs are described as having connections to people in powerful positions, related undoubtedly to the number that are asked for expert input (49.0%) and that participate in advisory groups (35.0%). These ongoing relationships via funding and participation as experts and advisors—not just as recipients of services or treatment—in policy decisions, allocation of resources, and guiding principles and philosophies may have the most potential for reducing stigma within, and perhaps outside of, mental health systems.

**Exemplary Programs**

**Exemplars.** Space considerations preclude providing detailed information on all 36 exemplars. The top five are described briefly below, followed by an analysis of distinguishing qualities identified by the panel for the entire group of exemplars. The text in quotes is derived from nomination and program materials and is included as illustrative rather than evaluative. A list of the exemplary programs that received more than 2+ votes is included in the appendix.

**Andy Zenke Youth Empowerment—Youth Radio**

KDNK, Carbondale, CO. In collaboration with two local nonprofit public radio stations, this project involves students from several high schools with mental health, educational, human services, and broadcasting professionals in the production of weekly radio programs devoted to both general and specific mental health topics. A nonprofit organization that receives funding from local and State mental health authorities, private donations, and local high schools is the umbrella for the project. Now 4 years old, the project involves about 30 students per weekly program and has expanded to include video as well as audio programming. "It helps youth to have a voice in the community, to learn team building and life career skills, as well as counseling to support recovery."

**Central Iowa Players Stigma Busters Drama Troupe, Des Moines, IA.** Founded in 1989, the Stigma Busters is a volunteer improvisational theater group that...
performs widely in the Midwest and offers training and workshops. It is directed by a professional actor/director and is affiliated with NAMI of Iowa and the Rainbow Center, a psychosocial clubhouse. “Performances consist of funny, dramatic, sometimes poignant, scenes covering a wide range of events from the player’s experiences as clients of the mental health system and from other aspects of their lives. . . . We are a theater group, not a therapy group. It just happens that some of the side effects are therapeutic. We work hard at perfecting our craft, mirroring the world as we see it, and as it sees us. Our results are powerful and real. . . . We touch a lot of people—we put a face to mental illness.”

Georgia Peer Specialist Certification Project, Atlanta, GA. This program is a joint effort of the Georgia Division of Mental Health, Developmental Disabilities and Addictive Disease, and the Georgia Mental Health Consumer Network, and has been funded since 2001 by Substance Abuse and Mental Health Services Administration (SAMHSA). “It is the mission of the Georgia Peer Specialist Certification Project to identify, train, certify and provide ongoing support and education to consumers of mental health services to provide peer supports as part of the Georgia mental health service system and to promote self-determination, personal responsibility and empowerment inherent in self-directed recovery.” To date, 119 peer specialists have received training and are employed as specialists in various sectors of the mental health system. The training is intensive and offered several times per year, as are continuing education workshops for already certified peer specialists. The project operates a comprehensive Web site and has developed an extensive curriculum.

Mental Health Empowerment Project, Albany, NY. The Mental Health Empowerment Project is a consumer-run nonprofit agency that provides a wide selection of services to consumers and providers. It sponsors regional conferences; offers training; creates research-based publications; works with the New York State Office of Mental Health to bring about systems change; facilitates the development of self-help groups; and provides technical assistance, instruction, and guidance to mental health professionals, consumers, families, and others on self-help, mutual support, and recovery. The six annual regional conferences alone draw 1,500 attendees per year. The program maintains a wide-ranging Web site and Web-based materials and has consulted nationally.

Regional Transportation District, Denver, CO. Developed in 2002 in response to a consent decree initiated by the Colorado Cross-Disability Coalition, this training program for bus drivers and other Regional Transportation District employees focuses on all disabilities, not solely psychiatric disorders. The program consists of slides, written narration, and music and is offered by a Regional Transportation District human resources professional in collaboration with the disability coalition. “This is an unusual but highly effective program. . . . I have been involved in disability rights issues and training since 1987 and I have never seen a piece as good as this . . . . The focus is on transit, but the presentation is the most amazing disability awareness piece that I have ever experienced.”

Exemplary Qualities. The panel members spent a good deal of time in discussion and analysis of the qualities that led to their selection of the exemplars. The essential question was: What makes a program exemplary? The results are summarized below.

Principles. Clear articulation and foregrounding of the fundamental principles of the program or project was paramount. Those principles that were of particular importance to the panel were inclusion; empowerment; human and civil rights; recovery; choice; self-determination; and respect for different philosophies and perspectives regarding psychiatric disorders, medication, treatment, and related issues. The principles make clear that the program’s goal is not primarily recruiting for treatment but rather addressing the needs of community members.

Language. “One word can make such a difference,” said one panelist. Language conveys principles. Language that is respectful of difference, oriented to abilities and strengths, person centered, easily understood, accurate, and evocative is a hallmark of exemplary approaches.

Power. Power includes the distribution of authority in the program or project and the recognition that inequities in power are central to discrimination and stigma. Consumer survivor- and person-centered organizations, as well as programs where authority is equally shared between consumer survivors and others, indicated to the panel that considerable power was being shared by consumer survivors and others.

Tangible resources and specific issue focus. Housing, jobs, transportation, income, health care, and other tangible resources are real-world issues faced widely by consumer survivors, and their absence contributes to and reflects discrimination. Likewise, neighborhood opposition to residential services and the passage or defeat of specific legislation are examples of specific issues addressed by exemplary programs. Making a real difference in real people’s lives is key.

Personal and interpersonal opportunities and contexts. Creating ongoing contexts where consumer survivors and others interact as equals, where consumer survivors have valued roles, and where their narratives are as valued as other “evidence” was highlighted by the panel.
“We are the evidence,” relayed one panelist in endorsing narrative-based practice.

**Direct benefits for participants as well as audience.** Work on antistigma and antidiscrimination activities should empower, heal, engage, and otherwise contribute to the pride and well-being of the participants.

**Community connections and partnerships.** Connections and embeddedness within the community—and coalitions and collaborations with local, State, and national partners—increase impact, contribute vitality and stability, and otherwise enhance exemplary programs. The goals are for consumer survivors to be valued, skilled, and equal citizens via these projects.

**Health promotion.** Prevention and wellness are recognized and promoted within outstanding programs.

**Expression through humor and drama.** Drama and humor can express what is otherwise inexpressible or difficult to convey and add crucial dimensions to the representation and understanding of the experiences of discrimination and stigma. Humor can temper the message while still conveying it.

**Reach, visibility, and impact.** Both quality and quantity of reach, visibility, and impact are of value in exemplary programs. Programs in schools; training and consultation with providers, political decision makers, and researchers; and radio and television programs are examples cited by the panel.

**Innovation and growth.** Ingenuity and creativity, vitality, longevity, and potential of the organization or program are hallmarks of exemplary programs. The panel looked for projects that embodied these qualities in various ways such as novel approaches that do not necessarily “lead with the illness,” program growth and duration, plans for future actions, ability to adapt to changing circumstances, and formation of coalitions across disability and other activist boundaries.

It is inevitable, and admittedly tautological, that the qualities identified above mark the exemplars. Nonetheless, these principles provide a potential working foundation for the development of new and the sustenance of current discrimination and stigma reduction efforts. While not subjected to rigorous scientific assessment of their effectiveness, the programs that embody these qualities have met the important tests of enduring and prospering over time and of earning the enthusiastic regard of their local communities.

There are few apparent noteworthy conceptual differences between the exemplars and other nominees. Perhaps most interesting are the operational differences between exemplary and other programs, but these are qualitative in nature rather than of statistical significance. We briefly review these because so little is known about the operational sphere of stigma reduction in the community. Exemplary programs were more likely to have grown, and more of them had been in existence for over 2 years than the other nominees. This may be taken as a measure of their impact, vitality, and connectedness to the community. Indeed, exemplars were more likely to be funded by and connected to local mental health authorities (36.1% vs. 25%) and the United Way (8.6% vs. 3.3%) than the other nominees.

Fewer exemplary programs than other nominees had family members as participants (33.3% vs. 43.9%) but as many involved health and health-related professionals. This may be due to the presence of 19 NAMI In Our Own Voice programs in the other nominees’ part of the sample. At the same time, fewer exemplary programs than other nominees reported consumers as participants (75% vs. 84.4%). This may be due to their coalition building with other activist groups and their involvement in other-than-psychiatric-disorder issues as a means of integration and normalization. Finally, the exemplars and other nominees appear to be addressing somewhat different audiences. More exemplary programs had school and student audiences (45.5% vs. 27.8%), and more other nominees were presenting to church or religious groups, service groups, and the community at large. This suggests again that the exemplars were engaged in somewhat more targeted and focused activities.

**Limitations**

The study reported here has limitations that necessarily temper the generalizability of the findings. The work was limited in scope, time, and resources because of the nature of the project funding. The efficacy of the programs that were nominated was not assessed with standardized research instruments. The response rate was lower than expected, and we undoubtedly undersampled consumer survivor-only programs, along with others that preferred terminology other than “stigma.” The deliberately inductive approach was appropriate for a preliminary effort to gauge local assessments of excellence in discrimination and stigma reduction programs but did not provide the opportunity to empirically test the derived exemplary qualities in relation to efficacy. A different consensus panel might have selected different exemplars, but in view of the similarities among nominees and the agreement among the panel, it is doubtful that the findings would be altered significantly.

**Conclusions**

Corrigan and Penn (1999) identified three approaches to altering stigmatizing views of severe mental illness: edu-
cation, contact, and confrontation or protest. Each of these is in evidence, in varying combinations, in the sample. Arguably, the programs in the sample support experimental research findings to the extent that contact and education, particularly ongoing contact between and among equal partners with actual decisional authority, seem to have the desired impact. The direct benefits to consumer survivors of the organization of, operation of, and participation in these efforts can hardly be overestimated. One of the key issues is how to spread the kinds of relationships, opportunities for accomplishment, and flow of healing experiences that happen in these projects to the broader landscape of daily life.

In this preliminary sampling of the nature, extent, and qualities of antidiscrimination and antistigma programs nationally, the most impressive observation is that noteworthy efforts are taking place across the country. There is demonstrable consensus, illustrated by the many conceptual and operational elements held in common, among the programs we reviewed. The exemplars have similar foci and qualities: training for and by consumer survivors; dramatic performances; programs for and by children and adolescents; various means of challenging popular views of people with psychiatric disorders; activities explicitly directed at countering discrimination in employment, housing, and community life; connections to a variety of community and mental health agencies; and engagement in broader disability coalitions. These programs endorse and practice empowerment, assertion of authority, and risk taking by the consumer survivor participants, and thus perhaps most important, represent a direct benefit to the participants through their engagement in the enterprise. A wide range of people, with diverse perspectives, using a variety of means and methods, are working together toward increasing the life opportunities and well-being of people who have a diagnosis of psychiatric disorders.

The extent to which consumer survivors are central to this enterprise, and the extent to which empowerment, equity, and self-determination are held in common, are also apparent. Emerging as intriguing activities among the nominees are consulting and training—interventions that combine education with extended contact. This deserves attention because it signifies also the elements of equity and empowerment, of impact, and of potential for systems change as consumer survivors function in the roles of experts, advisors, and influences on decision-making processes and in treatment or services settings. The willingness of increasing numbers of mental health systems and providers to engage with consumer survivors in these relationships signals significant positive shifts in attitudes and perspectives. In the same vein, State and local mental health agencies are devoting resources and support to these groups and individuals to a gratifying and promising extent. The current fiscal disasters in most States give cause for grave concern about the future availability of resources to continue this work.

There are differences in philosophies, values, and principles within this movement. The vocabularies of education for acceptance and understanding sometimes stand at odds with the language of protest, rights claims, and targeted change. Adapting and implementing the findings from controlled, empirical research on stigma reduction may prove problematic if implemented without consideration of this powerful context and these deeply held views. At the same time, further investigation into the means and mechanisms for altering prejudice and discrimination toward people with psychiatric diagnoses should not be limited by political and ideological divides.

Over the centuries, the predominant theme of efforts to reduce psychiatric stigma can be summarized as follows:

1. Humanitarian, human rights, and civil rights
2. Education
3. Proximity: increase contact, hospital closure, community treatment
4. Legislation: ADA, right to treatment, forced treatment
5. Medicalization, brain disease, chemical imbalance
6. Empowerment, recognition, and self-advocacy

The programs we reviewed employ many of these approaches, in various combinations. On the whole, we detected a shift in emphasis from stigma to discrimination—from a focus on stigma associated with illness per se toward the vocabulary and perspectives of discrimination, including an emphasis on human and civil rights and empowerment and self-advocacy. The challenges for further progress are many, but apparently there are already valued local efforts across the nation. Learning from and building upon these foundations should enhance future research and practice in stigma and discrimination reduction. Community collaboration, diversity of perspectives, and enduring engagement with citizens and health professionals seem to be keys to success and represent an emerging era of new approaches.

The observations of one consumer survivor panelist encapsulate the changes in approach we observed:

I think that presentations, descriptions, will have a limited effect on this issue [stigma]. That is because I believe the effects of speeches, presen-
tations are small, and at best have only a limited purpose. I do not believe that most speeches, presentations, et cetera have more than a brief, ephemeral effect. . . . A speech or presentation will not succeed in changing long-standing and comfortable patterns of behavior.

They can speak and spark new ideas that the audience can go out and test in the community. Speeches, presentations, and other "nonnormal events" can shape a mind, but in "normal" life, the community is where the shaping takes a more permanent form. In this case, the reality and the image are the same, and the best way to improve a group's image is to improve the reality of the group's situation. Thus, the best places for an anti-stigma campaign to work would be in the community itself, on the community. Working on the image, and working on the tangible issues are in many ways working on the same thing. However, just working on one or the other does not yield the results of a combined approach. The anti-stigma movement, in my opinion, needs to get real (emphasis in original).

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**Appendix. Other Exemplary Programs**

**Advocacy Initiative Network of Maine, Maine Leadership Academy, Bangor, ME.** One panel member described this as “a consumer-led, consumer-driven organization dedicated to strengthening consumers’ voice in Maine through education, training, and support.” Offering clearly articulated values and activities, the program receives funding from the State mental health authority and the Center for Mental Health Services.

**Anti-Discrimination Projects of the Mental Health Association of New York State, Community Mental Health Promotion Project, Albany, NY.** A wide range of initiatives, services, and resources based on local teams and local leaders and statewide coordination are involved. An extensive Web site describes programs that include Parents with Psychiatric Disabilities, education for children, statewide advocacy, statewide training and education, consumer and business outreach, and a clearinghouse for information and resources. It is funded by the Governor’s Council on Physical Fitness and Health, the Missouri Coalition of Mental Health Providers, and the University of Missouri Extension.

**Contra Costa Campaign to Address Discrimination and Stigma/California Campaign to Address Discrimination and Stigma, Contra Costa, CA.** Activities include collaboration with local and State stakeholder groups, speakers bureau, media watch, visual and interactive educational presentations, teaching at local universities, and working with faith communities. Funding comes from the local mental health authority and from member organizations.

**GSM Players, Keene, NH.** This is a drama troupe of regional renown that also operates a crisis respite program as an alternative to hospitalization. Audiences include churches, schools, and universities nearby. It is funded by the State mental health authority and donations.

**Look at My DisAbility, Birmingham, AL.** This is a statewide campaign that includes I Can Vote, a voter registration initiative for people with psychiatric disorders. Billboards statewide, a poster campaign, and radio public
service and education spots are included. It is funded by Alabama NAMI and the State of Alabama.

**Mental Health Forum for Kids by Kids About Kids, Jacksonville, FL.** This collaborative effort of the Mental Health Association of Northeast Florida and a local teacher also includes local law enforcement and university faculty. Students engage in research on various psychiatric disorders and present "grand rounds" to each other and professionals. Other participants offer lectures and educational material. It is funded by the United Way and private donations.

**Mental Illness: It’s Not What You Think, Columbia, SC.** Activities include media campaigns, speakers bureau, art of recovery shows on-line and on the ground, media watch, an extensive Web site, and teaching in college journalism programs. It was developed and initially funded by the South Carolina Department of Mental Health.

**Open Minds, Open Doors, Mental Health Association in Pennsylvania and the Pennsylvania Mental Health Consumers Association in collaboration with 12 other stakeholder groups, Philadelphia, PA.** Various activities include publication of an employer guide, speakers bureau, and video and slide presentations. Focusing on education, tolerance, and legal rights, it receives funding from the State mental health authority.

**Quad City Stigma Busters, Davenport, IA.** The group uses improvisational theater to educate audiences about people with mental illness. Developed with the guidance and training of the Central Iowa Players (described above), it performs at schools, community agencies, and professional societies, and at national conferences. It completed an effectiveness study with high school and college students. Donations, the local mental health agency, and the local NAMI provide the funding.

**Welcome House Stigma Fighter Players, Shelbyville, KY.** Actors in this drama troupe from a psychosocial rehabilitation program use role-play, creative art, and structured group exercises to entertain and educate. They appear statewide, nationally, and internationally and have received numerous awards from State advocacy organizations. The group is funded by the local mental health authority and donations.