Important Research from the National Consortium on Stigma and Empowerment

www.NCSE1.org
Illinois Institute of Technology, Chicago, IL
Since 2000, investigators of the National Consortium on Stigma and Empowerment have been working with advocates to examine strategies for eradicating the stigma of mental illness, replacing it with affirming attitudes and behavior that reflect recovery and self-determination. Funded continuously by NIMH, NCSE has conducted more than 50 studies yielding more than 100 peer-reviewed papers. In the past year, four have emerged with especially important findings and conclusions. These are reviewed here.


This article reports on a meta-analysis examining the effects of different anti-stigma approaches. Findings show that while overall, both education and contact have positive effects on reducing stigma, contact seems to yield better change, at least among adults. In particular, face-to-face contact, rather than contact by video, was most effective. Education, on the other hand, was more effective than contact for adolescents.


A major public health priority is to eliminate stigma’s egregious effects on life opportunities for people with mental illness. Research shows that contact-based anti-stigma programs are among the most effective, calling for clarity to define the components of consumer-directed anti-stigma programs. This study identified key ingredients for consumer-directed anti-stigma programs.


This paper reviews the research that supports the assertion that identifying with one’s mental illness and publicly disclosing it may promote empowerment and reduce self-stigma. This paper discusses a program that might diminish stigma’s effect by helping people to come out with their experiences with mental illness, treatment, and recovery.


This review explores whether the increase in knowledge about the biological correlates of mental disorders over the last decades has translated into improved public understanding about mental illness and more social acceptance of persons with mental illness. While there has been a trend toward greater mental health literacy, in particular towards a biological model of mental illness, this seems not to have resulted in better social acceptance of persons with mental illness.

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Challenging the Public Stigma of Mental Illness: A Meta-Analysis of Outcome Studies

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Objective: Public stigma has pernicious effects on the lives of people with serious mental illnesses. Given a plethora of research on changing the stigma of mental illness, this article reports on a meta-analysis that examined the effects of anti-stigma approaches that included protest or social activism, education of the public, and contact with persons with mental illness.

Methods: The investigators heeded published guidelines for systematic literature reviews in health care. This comprehensive and systematic review included articles in languages other than English, dissertations, and population studies. The search included all articles from the inception of the databases until October 2010. Search terms fell into three categories: stigma, mental illness (such as schizophrenia and depression), and change program (including contact and education). The search yielded 72 articles and reports meeting the inclusion criteria of relevance to changing public stigma and sufficient data and statistics to complete analyses. Studies represented 38,364 research participants from 14 countries. Effect sizes were computed for all studies and for each treatment condition within studies. Comparisons between effect sizes were conducted with a weighted one-way analysis of variance.

Results: Overall, both education and contact have positive effects on reducing stigma for adults and adolescents with a mental illness. However, contact was better than education at reducing stigma for adults. For adolescents, the opposite pattern was found: education was more effective. Overall, face-to-face contact was more effective than contact by video.

Conclusions: Implications of findings for the continued development of anti-stigma programs are discussed.

Stigma has broadly harmful effects on the lives of people with mental illness. Public stigma (the prejudice and discrimination endorsed by the general population that affects a person) has been distinguished from self-stigma (the harm that occurs when the person internalizes the prejudice) with attempts to craft separate interventions for each type of stigma (1,2). Advocates from around the world have been trying to erase the public stigma of mental illness for more than 50 years (3). In the 1950s, Cummings and Cummings (4) used group discussions and films throughout a small Canadian town to affect mental illness stigma. Since 1996, the World Psychiatric Association has promoted its Open-the-Doors programs, which has produced a slew of evaluations (3,5). Australia’s beyondblue initiative to raise awareness and reduce stigma surrounding depression has been in place for more than a decade, whereas Canada and the United Kingdom have jumped into the anti-stigma fray only in the past couple of years.

Background
The United States first systematically pursued anti-stigma campaigns after the 1999 White House Conference on Mental Health. American efforts against stigma have soared given the energy and resources of professional groups (the American Psychiatric Association and American Psychological Association), advocacy groups
(such as the National Alliance on Mental Illness [NAMI] and Mental Health America), pharmaceutical companies (Eli Lilly), and government bodies (the Substance Abuse and Mental Health Services Administration and the National Institute of Mental Health). Research has begun to examine the effect of various programs intended to erase public stigma. This article reports on a meta-analysis of findings reported in the available research literature.

Three approaches to change
Approaches to changing public stigma have been divided into three paradigms on the basis of a review of social- psychological research related to racial-ethnic and gender minority groups: education, contact, and protest (6). Educational approaches to stigma challenge inaccurate stereotypes about mental illnesses, replacing them with factual information (for example, contrary to the myth that people with mental illnesses are homicidal maniacs, the difference in the rate of homicides by people with serious psychiatric disorders versus the general public is very small). Educational strategies have included public service announcements, books, flyers, movies, videos, Web pages, podcasts, virtual reality, and other audiovisual aids (7,8). Some benefits of educational interventions include their low cost and broad reach.

A second strategy for reducing stigma is interpersonal contact with members of the stigmatized group. Individuals of the general population who meet and interact with people with mental illnesses are likely to lessen their levels of prejudice (9). Social-psychological research has identified factors that seem to moderate contact effects (10,11), including one-to-one contact so that people who engage with one another can learn of similar interests and potentially cultivate a friendship (12,13), contact that includes a common goal (14), and interactions with a person who moderately disconfirms prevailing stereotypes (15,16).

Social activism, or protest, is the third form of stigma change we examined. Protest strategies highlight the injustices of various forms of stigma and chastise offenders for their stereotypes and discrimination: “Shame on us all for perpetuating the ideas that people with mental illness are just ‘big kids’ unable to care for themselves.” There is anecdotal evidence suggesting that protest can reduce harmful media representations (17). However, some research implies protest campaigns that ask people to suppress prejudice can produce an unintended “rebound” in which prejudices about a group remain unchanged or actually become worse (18–20). In one set of studies, Macrae and colleagues (18) found that research participants directed to suppress stereotypes about skinheads showed greater stereotype activation and increased distance from members of that group.

Outcomes of public stigma change have been assessed in several ways, with self-reported social-cognitive measures dominating (21–23). These are sometimes understood in terms of a simple path model: attitudes, affect, and behavior (9). Attitudes reflect the stereotypes about mental illness and include ideas about blame, dangerousness, and incompetence. Affect concerns the emotional reaction to attitudes: dangerousness begets fear, and blame yields to anger. Discriminatory behavior results from stereotypic attitudes and affect; for example, the public is hesitant to employ (24–28) or to rent property (28–31) to people with mental illness. Behavior per se is a difficult construct to assess because most studies do not have resources to observe actual responses after stigmatizing attitudes and affect. This kind of assessment requires some form of independent observation in an overwhelming number of settings and times. As a result, many studies fail to assess change in discriminatory actions. More likely, self-report measures used as outcome indicators in public stigma change studies represent behavioral intentions—the self-reported likelihood that people somehow anticipate distancing themselves or otherwise avoiding a person with mental illness (22).

Past reviews
Two reviews have attempted to make sense of the body of research on public stigma change. Holzinger and colleagues (32) summarized 51 studies of interventions targeting public stigma conducted in real-world settings with members of the general public. They did not include investigations using experimental or other laboratory designs. Documents were located through review of PubMed, gray literature, and the Internet; psychological databases (PsycNET) and replication studies were excluded. They concluded that education and contact conditions seem to have positive effects on attitudes. Their findings on the impact on behavior were less clear.
Outcomes in this review were coded solely as positive or negative, with no effect sizes, so inferential statistics were not used to more carefully make sense of education versus contact effects. Moreover, no careful coding schema was used to summarize treatment methods or outcome variables. The list of studies also did not include several prominent investigations in the field. Another older review focused solely on contact effects (33). The review considered 22 studies, dividing them into retrospective (reporting the effects of previous contact) and prospective (the effects of planned contact where an advocate interacts with a group). The authors concluded that both types had robust inverse effects on stigma. Like the review by Holzinger and colleagues, however, the Couture and Penn study (33) did not determine effect sizes or provide any careful codes of research design. Moreover, retrospective studies would not fall under the rubric of stigma change as examined here—that is, a planful effort to change stereotypes, prejudice, and discrimination of targeted groups.

Given this background, we pursued a meta-analysis of strategies to change public stigma, keeping several aims in mind. We sought to describe the degree to which the social-cognitive model of stigma (attitudes, affect, and behavior intention) has been tested. Consistent with research on the prejudice related to ethnicity and gender, we hypothesized that contact strategies would yield significantly better effects than education (6). We describe the quality of research designs used to examine these questions. Two-by-two (pre-post) randomized controlled trials offer the most rigorous test of contact versus education; hence, effect sizes from just those studies were separately examined. We examined the effects of milieu for establishing contact—via video or in person—and hypothesized that the grassroots nature of meeting in person would lead to better effects. We also tested how anti-stigma programs influence the stigmatizing attitudes and behavioral intentions of adolescents, an important target group.

**Methods**

**Selection**

We used the Centre for Reviews and Dissemination’s guidelines for systematic reviews in health care (34) to organize and conduct the meta-analysis. The guidelines include a comprehensive algorithm for locating relevant studies in the broadest sphere of published documents, coding the studies in a comprehensive and reliable manner, and determining valid effect sizes that serve as the foundation for analyses of important research goals. We adopted a snowball strategy for finding studies. We began with databases most likely to yield peer-reviewed or mentor-reviewed papers: PsycNET, PubMed, Scopus, and Dissertation Abstracts. Searches yielded primary sources, and we then reviewed the reference sections of those sources to identify additional candidates for consideration. Searches focused on articles from the inception of the database up to October 2010. We also made a special effort to identify articles in languages other than English. Several articles identified in the above searches were reviewed by colleagues bilingual in Chinese, German, French, Polish, and Spanish. In addition, we searched several Indian databases (Scientific Journal Publishing in India, HRH Global Resource Center Web page, connectjournals.com, Indian Academy of Sciences, Indian Institute of Science, Indian National Science Academy, and Indianjournals.com) and Chinese databases (the China National Knowledge Infrastructure and Chinese Electronic Periodical Services). Despite this effort, only two German language articles were found to meet inclusion criteria. Finally, we cross-walked our collection of articles with the recent review by Holzinger and colleagues (32).

We used three sets of search terms: stigma, mental illness, and change program. Mental illness was searched using the broad rubric plus more specific terms like “mental disorder” or individual diagnoses. Along with “change program,” seven additional search terms were used that represented specific programs (education or contact) or more general synonyms (stigma reduction or anti-stigma program). Using the search terms, we located more than 8,700 documents, and 72 of them ultimately provided usable data to address our goals. The review and winnowing process is summarized in [ID]FIG1[/ID]Figure 1. Note that most articles yielded multiple effect sizes, depending on condition, trials, and outcome variables therein.

**Coding**
A code book was developed to summarize each study; codes represented key concepts about public stigma change described in our introduction. Specific codes included descriptors of research participants, research design, type of stigma change program, outcome measures, and moderating variables. Type of anti-stigma intervention was indicated by one of three codes: protest, contact, and education. Clear definitions of interventions were provided to ensure that studies were grouped appropriately (these definitions and the code book are available from the first author).

We coded for type of outcome variable in terms of attitude, affect, or behavioral intention. We entered number of research participants assigned to each group and target of the intervention. Some studies looked at developmental issues; therefore, we coded for whether studies included children and adolescents. Some studies looked at effects on power groups, including employers, health care professionals, and police officers. Demographic characteristics of targets were also entered, including gender, age, race-ethnicity, and education level. Two graduate student raters were trained on the coding schema and had to meet the reliability criterion on five articles ($k=0.84$) before working independently. After review of more than 30 articles, interrater reliability was checked again for drift but remained high ($k=0.94$).

**Effect size analysis**

The effect size used in this study was the standardized mean difference ($\Delta$) comparing the means of persons who received the intervention versus a contrast condition, divided by the within-group standard deviation of scores. Effect sizes were scaled so that a positive effect size would indicate less stigmatizing attitudes among those who received the intervention. Data were obtained from a variety of research designs, so effect sizes were computed with all available information from each design (36,37). Effect sizes were computed from means and standard deviations where available. In other cases, effect size was computed from available statistics ($t$ or $F$) or $p$ values with the use of formulas appropriate to each research design (38).

A few studies included more than one treatment condition. Wherever conditions represented different types of intervention, a separate effect size was computed for each intervention that met the inclusion criteria. Otherwise, effect sizes were averaged to produce a single effect size for the type of intervention. Many studies included multiple outcome measures. Variables representing distinct outcome constructs were maintained as separate effect sizes. When multiple measures of the same construct were provided, these were included as separate effect sizes for subsequent analyses. Comparisons between effect sizes were conducted with a weighted one-way analysis of variance (ANOVA) from the SPSS macro MetaF (39).

**Results**

We found 72 articles that were related to changing the public stigma of mental illness with data suitable to the meta-analyses described herein (7,40–109). Table 1 provides summary statistics of these studies, including mean frequencies of demographic characteristics determined by summing frequencies from each study that provided a specific demographic and dividing by total number of studies. We also determined mean and standard deviation of participants’ average ages in a similar manner. The 72 articles represented 79 independent studies with 38,364 research participants from 14 countries; by continent, they were from Europe (N=22,179), North America (N=14,307), South America (N=63), Asia (N=1,299), and Australia (N=516). There were none from Africa. The median number of research participants per study was 150.0 ($\text{mean} \pm \text{SD} = 540.3 \pm 1,279.3$). Articles were published from January 1972 to October 2010. The literature search yielded 612 effect sizes. Of the research participants, 58.7% were female, and most were European or European American (>60%). The participants were mostly single (>70%) and students (>60%) with a college education or higher (>60%).

An important goal of anti-stigma programs is to strategically target groups who, by virtue of age or role, have importance in terms of the broad stigma change picture (110). For example, employers who endorse stigma may be less likely to hire people with mental illness and therefore might be important targets. Table 1 provides the frequency with which the 79 studies targeted specific groups. Although seemingly an important group, children under age 12 were rarely the focus of stigma change (8%); adolescents, on the other hand, were far more common targets, with almost 25% of studies we examined targeting stigma among teenagers.
Professionals (4.7%) and students in professional programs (8.5%) were relatively more common targets of stigma change, as were criminal justice professionals (7.2%). This information on targeted groups was the only proxy coded for setting in which a specific anti-stigma program was conducted.

One way we sought to index the quality of the anti-stigma programs was whether there was evidence of some sort of manual or training guiding the program. About 40% of studies reported use of an anti-stigma program manual. About 14% acknowledged some sort of training of program facilitators. We also coded for studies that checked fidelity of the anti-stigma program and found none.

An important finding of meta-analyses is an audit of the type of outcome measures used to assess affects. The bottom of Table 1 provides frequencies with which constructs were examined in individual studies. They are divided into the three outcome areas: attitudes, affect, and behavioral intentions. Frequent measures of attitudes included dangerousness, competence, responsibility, and poor prognosis. Affect was much less often assessed and was represented by proxies of fear and anger. Behavioral intentions were most often represented by measures of avoidance. We coded psychometric values of assessments where available; summaries are provided in Table 1 by outcome type (see table footnotes). Test-retest reliabilities were not found for measures of affect; six alphas were obtained for this domain, with the mean being high (> .8). Thirty or more test-retest reliabilities or alphas were provided for measures of attitudes and behavioral intentions; all of their means were satisfactory, exceeding .725. The next section summarizes effect sizes by anti-stigma approach. Each analysis provides both an overall result (across all outcomes), as well as separate results for each type of outcome measure.

Effects of contact and education on public stigma change
The means and standard errors of effect sizes (d) are organized in Table 2 by anti-stigma approach; the table also includes the number of effect sizes gleaned from the literature per approach (K). Note that this number was often above the 72 articles and reports and 79 individual studies found from the review because most investigations used multiple dependent measures or comparisons to test for differences. [A forest plot summarizing the effect sizes from the overall analysis is provided online as a data supplement to this article. The graph depicts the effect size estimate from each study, along with the 95% confidence intervals (111).]

Two kinds of significant differences were examined in this meta-analysis. The first was whether the effect size differed significantly from zero effect. Mean d, representing the overall effect for protest, was .099, which did not differ significantly from zero effect, suggesting that protest led to no significant change in outcome. Note that Cohen (112) defined effect sizes as negligible (< .10), small (.10– .30), medium (.30– .50), and large (> .50). Only four effect sizes representing protest effects (K=4) emerged from the literature, and they were all obtained from only one study. Hence, for the remainder of the analyses, we considered only the pattern of effect sizes for education versus contact.

Table 2 shows overall effect sizes for contact and education each significantly differed from zero (p<.001) and were relatively small (between .10 and .30). This was based on 431 and 177 d values for education and contact, respectively. The second kind of significant difference examined in this study was between the distribution of effect sizes for anti-stigma groups. Results of a random-effects, one-way ANOVA showed mean effect sizes differed significantly between protest, education, and contact approaches to changing public stigma. However, an additional random-effects ANOVA failed to show that effect sizes between contact and education differed significantly. Mean d also differed significantly from zero for both approaches when change in attitudes was assessed and yielded medium effect sizes. Table 2 includes the weighted one-way ANOVA for difference in these d values (total K=373) and showed a significant difference (Q=6.17, p<.05) for attitude effects, with contact with persons with mental illness leading to greater improvement in changing public stigma. Education was shown to yield significant improvements in the affect and behavioral intention domains as well, with small effect sizes. Contact yielded significant improvements in behavioral intentions but not in affect. Mean d values did not differ significantly between education and contact across affect and behavioral intentions.

Variability of design quality across studies is a concern in meta-analyses, because effect sizes arise out of research studies that differ in experimental rigor. Meta-analysts have written much about indices of design
quality and seem to agree that studies using randomized controlled trials (RCTs) require similar procedural manipulations to make them relatively similar and methodologically strong (113). Thirteen articles reported RCTs, yielding 187 effect sizes. These values are summarized in the bottom of Table 2. Once again, the mean overall d for education and contact was significantly different from zero effect (p<.01 and .001, respectively). Moreover, results of the weighted one-way ANOVA were significant, with the mean effect size for contact being significantly greater than for education (p<.05). Table 2 also includes effect sizes by attitude and behavioral intention. Education and contact yielded effect sizes significantly greater than zero for both constructs. Weighted one-way ANOVAs were significant for attitudes and behavioral intentions (p<.05), with mean effect size for contact larger than that for education in both instances.

**Video versus in-person effects**
Table 2 includes Qw as an index of homogeneity, or the degree to which variance across studies within a subgroup is larger than expected due to chance. Significant Qw values were found for half the distribution of effect sizes for contact approaches (top of Table 2), and for three out of four of the d distributions for the RCTs. These findings suggest that moderators may further explain some of the significance of the contact effect. Our review of the literature suggested one variable that might moderate effects: the means of contact (contact in person versus via video). Namely, was contact from someone with mental illness provided in person or on videotape? Table 3 summarizes mean d values for overall effect size as well as for attitudes and behavioral intentions across studies that used contact in person versus by video.

The mean d for overall effect size was significant for both types of contact. A weighted one-way ANOVA showed that compared with contact by video, in-person contact had a significantly greater effect size (p<.001). Moreover, effect sizes for the two types of contact were significantly greater than zero for attitudes and behavioral intention. One-way weighted ANOVAs showed in both cases that effect size after in-person contact was significantly greater than that yielded by videotaped contact.

**Effects on adolescents**
Some advocates believe that anti-stigma programs for children are an effective way to prevent stigma from emerging in adulthood; although very few studies targeted children under age 12, almost a quarter (N=19) targeted adolescents. Table 3 summarizes effect sizes across education and contact conditions for this age group. Findings were a bit different from those reported for overall samples. Mean effect sizes showed education and contact both led to significantly increased overall effects as well as to change in attitudes and behaviors. However, unlike the ANOVA for adults, the one-way weighted ANOVA examining mean effect sizes for attitudes showed education yielded a larger effect than contact. No significant differences were found in mean effect sizes for education and contact with overall effect size or behavioral intention.

Table 3 also shows results of in-person and video contact with adolescents; these findings mostly paralleled those of the total meta-analysis in the upper portion of Table 3. Effects by contact type led to significant changes in overall outcome. Moreover, the one-way weighted ANOVA showed that in-person contact yielded greater overall effects than contact by video. In-person contact yielded significant change in attitudes and behavioral intentions, whereas video contact showed significant improvements only in attitudes. A one-way ANOVA for difference in effect sizes for behavioral intentions yielded nonsignificant trends (p<.10), suggesting in-person contact had a bigger effect than video contact for adolescents.

**Discussion**
Although contact and education both seem to significantly improve attitudes and behavioral intentions toward people with mental illness, contact seems to yield significantly better change, at least among adults. This is especially evident in studies that used more rigorous research designs, such as RCTs. Mean effect sizes for contact when assessing overall effects as well as effects on attitudes and behavioral intentions were significantly greater than those found for education. Meeting people with serious mental illness seems to do more to challenge stigma than educationally contrasting myths versus facts of mental illness.
One additional finding—and the most important—emerged from the meta-analysis: face-to-face contact with the person, and not a story mediated by videotape, had the greatest effect. This was evident for overall impact as well as for changing attitudes and behavioral intentions. This finding juxtaposes two important agendas in stigma change: broad audience versus grassroots control. Videotaped contact has the potential for a broad audience: disseminating the video via a variety of online platforms and television networks exponentially increases exposure of the anti-stigma effort compared with face-to-face approaches. However, the social marketing campaigns that rely on videotaped contact diminish grassroots control of the effort. Social marketing campaigns are often managed by government and advertising consortia rather than by people with mental illness who are targeting key groups at the local level for meaningful stigma change. In-person contact leads to better effects, but both types of contact significantly diminish stigma. Those crafting an anti-stigma campaign need to balance relative effect sizes with population served and grassroots control issues.

Additional intriguing differences were found when we focused on contact and education effects on adolescents. Once again, both education and contact were shown to significantly affect stigma overall, as well as attitudes and behavioral intentions. However, contrary to the other findings across all studies, education yielded significantly greater effects on attitudes than contact did. Perhaps this difference emerged because adolescents’ beliefs about mental illness are not as firmly developed as adults’ and adolescents therefore are more likely to be responsive to education effects. Compared with adults, adolescents show more variance in response to stigma measures and hence have more room for change. What implications do these findings have for ongoing campaigns for children and adolescents? They may bolster the need for caution which many have voiced about using peers as contacts, that is, high school students telling their stories about mental illness and recovery. Advocates have been concerned about risks for persons with mental illness in this age group compared with risks for adults in similar circumstances. Still, it is unclear from the meta-analysis whether the relatively muted effects of contact compared with education occurred because the person providing contact to the adolescents was close to their age. Generally, similarity between contact and audience is needed for most stigma effects (110). Compared with adults, adolescents show more variance in response to stigma measures and hence have more room for change. What implications do these findings have for ongoing campaigns for children and adolescents? They may bolster the need for caution which many have voiced about using peers as contacts, that is, high school students telling their stories about mental illness and recovery. Advocates have been concerned about risks for persons with mental illness in this age group compared with risks for adults in similar circumstances. Still, it is unclear from the meta-analysis whether the relatively muted effects of contact compared with education occurred because the person providing contact to the adolescents was close to their age. Generally, similarity between contact and audience is needed for most credibility and greatest anti-stigma effects (110). Cohort and developmental differences need to be considered in future research on contact programs in schools. It is also important to note that in-person contact seemed to produce greater effects than video-based attempts.

We found that protest or social activism concerning public stigma was rarely examined in research. In part, investigators seemed to be “voting with their feet,” suggesting that protest is not a good strategy to affect stigmatizing attitudes and behavioral intentions. In fact, the effect sizes found in the meta-analysis did not show that protest yielded significant changes in stigma. Still, protest probably should not be discarded entirely. Although it is not an effective avenue for changing attitudes, it may be useful in suppressing behaviors that promote stigma, especially in the media. Programs like NAMI’s StigmaBusters have targeted stigmatizing advertisements, news stories, and entertainment through strategic letter-writing campaigns. Anecdotally, these seem to have had some effects—for example, one campaign led the American Broadcasting Company to pull its television drama Wonderland in 2000 after two episodes. The show stoked stereotypic connections between mental illness and violence. Research is needed to determine whether anecdotes like these translate to meaningful impact on stigma in the media.

Meta-analyses are known for their problems, and this one had its share. The 22 outcome measures summarized in Table 2 were reduced to three effect sizes, thereby losing theoretical and methodological sensitivity. Contact and education are complex processes, yet each was squeezed into a single mold for our analyses. We were unable to report separate analyses on follow-up effects because of the significant differences in their definitions in the relatively few studies that reported them. Despite the call for targeted anti-stigma programs, such audiences were not strategically sought in the studies we found on stigma change. Another way to target stigma change is by diagnostic group: messages that frame the stigma of schizophrenia versus the stigma of major depression. Programs with this kind of distinction were largely not present in the literature. Outcome was largely limited to self-report. Given that discriminatory behaviors are perhaps the most egregious of stigma’s impacts, examination of change in behavior was regrettably missing.
Conclusions
One of the benefits of reviews like these, and the methodological audits on which they rest, is the directions signaled for future research. Both education and contact have some value in stigma change. Future research needs to identify moderators of these effects. They include adjustments within the intervention (for example, the means of contact) as well as to the target of the intervention. Degree of exposure to the program is an important parameter. Greater resources are needed to go beyond psychological self-reports to observe actual behavior change.

One area not discussed in this review is the impact of multiple stigmas and how anti-stigma programs should be crafted to address the interaction of multiple prejudices—for example, mental illness and demographic characteristics (such as race, gender, or sexual orientation) or other health conditions (such as HIV/AIDS or physical disabilities). This concern brings us back to the grassroots goal, namely that stigma is a local issue shaped by the experience of mental illness in a variety of social contexts. Hence, stigma change, and evaluation of this change, must be conducted at the local level. This calls for future research that is dominated by community-based participatory research and investigations marked by partnerships between those skilled in research methods and local advocates.

Acknowledgments and disclosures
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**Figure 1** A summary of the review process guiding the meta-analysis

**Table 1 Key descriptors in 79 studies of countering public stigma**

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Frequency (%)</th>
<th>Range (%)</th>
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<tbody>
<tr>
<td><strong>Research participants</strong></td>
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<tr>
<td>Age (M±SD)</td>
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<td>Part-time</td>
<td>1.7±8.3</td>
<td>0–47</td>
</tr>
<tr>
<td>Student</td>
<td>69.0±45.2</td>
<td>0–100</td>
</tr>
<tr>
<td>Unemployed</td>
<td>1.9±5.8</td>
<td>0–29</td>
</tr>
<tr>
<td><strong>Educational attainment</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than high school</td>
<td>31.6±47.0</td>
<td>0–100</td>
</tr>
<tr>
<td>High school diploma or GED</td>
<td>5.8±13.6</td>
<td>0–59</td>
</tr>
<tr>
<td>Some college</td>
<td>46.0±46.9</td>
<td>0–100</td>
</tr>
<tr>
<td>4-year degree</td>
<td>11.8±24.0</td>
<td>0–100</td>
</tr>
<tr>
<td>Graduate degree</td>
<td>5.2±15.0</td>
<td>0–67</td>
</tr>
<tr>
<td><strong>Target of stigma change</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>College students</td>
<td>27.2</td>
<td></td>
</tr>
<tr>
<td>Children under 12</td>
<td>.8</td>
<td></td>
</tr>
<tr>
<td>Adolescents</td>
<td>24.1</td>
<td></td>
</tr>
<tr>
<td>Adults (&gt;18)</td>
<td>26.5</td>
<td></td>
</tr>
<tr>
<td>Professionals</td>
<td>4.7</td>
<td></td>
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<tr>
<td>Family members</td>
<td>.3</td>
<td></td>
</tr>
<tr>
<td>Professional students</td>
<td>8.5</td>
<td></td>
</tr>
<tr>
<td>Criminal justice professionals</td>
<td>7.2</td>
<td></td>
</tr>
<tr>
<td><strong>Quality of anti-stigma program</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anti-stigma manual (% yes)</td>
<td>40.1</td>
<td></td>
</tr>
<tr>
<td>Manual training (% yes)</td>
<td>14.2</td>
<td></td>
</tr>
</tbody>
</table>

**Outcome measure**

- Attitudes
  - Competence: 4.2
  - Dangerousness: 6.5
  - Empowerment: 1.0
  - Poor prognosis: 4.2
  - Responsibility: 4.2
  - Benevolence: 2.1
<table>
<thead>
<tr>
<th>Category</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>Negative perceptions</td>
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<tr>
<td>Personality</td>
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<tr>
<td>Credibility</td>
<td>0.3</td>
</tr>
<tr>
<td>Affectc</td>
<td></td>
</tr>
<tr>
<td>Anger</td>
<td>1.6</td>
</tr>
<tr>
<td>Fear</td>
<td>2.8</td>
</tr>
<tr>
<td>Pity</td>
<td>1.5</td>
</tr>
<tr>
<td>Shame</td>
<td>0.8</td>
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<tr>
<td>Behavioral intentionsd</td>
<td></td>
</tr>
<tr>
<td>Avoidance</td>
<td>10.9</td>
</tr>
<tr>
<td>Coercion</td>
<td>2.4</td>
</tr>
<tr>
<td>Help</td>
<td>2.4</td>
</tr>
<tr>
<td>Segregation</td>
<td>2.9</td>
</tr>
<tr>
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<td>2.1</td>
</tr>
<tr>
<td>Community health ideology</td>
<td>1.6</td>
</tr>
<tr>
<td>Social restrictiveness</td>
<td>2.4</td>
</tr>
<tr>
<td>Interpersonal ideology</td>
<td>0.8</td>
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</tbody>
</table>

a Values indicate percentage of studies that used a measure of attitude, affect, or behavioral intentions.
b N reported=44, test-retest reliability=.730±.16, N=37, mean α=.760±.15
c N reported=0, test-retest reliability was not applicable, N=6, mean α=.835±.09
d N reported=32, test-retest reliability=.755±.07, N=29, mean α=.811±.08
Table 2 Overall effect of anti-stigma programs and effects on attitudes, affect, and behavioral intentions in 79 studies*

<table>
<thead>
<tr>
<th>Anti-stigma approach</th>
<th>Overall*b</th>
<th>Attitudes*c</th>
<th>Affect*d</th>
<th>Behavioral intentions*e</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>d  SE</td>
<td>SD  K  Qw</td>
<td>d  SE</td>
<td>SD  K  Qw</td>
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<tr>
<td>All studies</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Protest</td>
<td>.099</td>
<td>.284 .096 4</td>
<td>.006</td>
<td>0</td>
</tr>
<tr>
<td>Education</td>
<td>.286***</td>
<td>.023 .304 431</td>
<td>.310***</td>
<td>.026 .291 280</td>
</tr>
<tr>
<td>Contact</td>
<td>.282***</td>
<td>.036 .583 177</td>
<td>.406***</td>
<td>.046 .611 93</td>
</tr>
<tr>
<td>Randomized controlled trials (N=13)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td>.153**</td>
<td>.034 .158 116</td>
<td>.207*</td>
<td>.054 .118 50</td>
</tr>
<tr>
<td>Contact</td>
<td>.363***</td>
<td>.069 .443 71</td>
<td>145.8***</td>
<td>.626***</td>
</tr>
</tbody>
</table>

*a d, adjusted mean effect size; SE, standard error of the mean effect size; SD, standard deviation of the mean effect size; K, number of effect sizes; Qw, homogeneity
*b Between-groups comparisons: all studies, Q=18.37, df=2 and 611, p<.001; RCTs, Q=4.80, df=1 and 186, p<.05
*c Between-groups comparisons: all studies, Q=6.17, df=1 and 372, p<.05; RCTs, Q=4.38, df=1 and 76, p<.05
*d Between-groups comparisons: all studies, Q=2.87, df=1 and 40, p=.20; RCTs, not applicable
*e Between-groups comparisons: all studies, Q= 4.80, df=1 and 192, p=.73; RCTs, Q=4.70, df=1 and 87, p<.05
**p<.05
***p<.01
### Table 3: Effectiveness of in-person versus video contact with a person with mental illness and effectiveness of education versus contact in anti-stigma programs for adolescents

<table>
<thead>
<tr>
<th>Anti-stigma approach</th>
<th>Overall&lt;sup&gt;a&lt;/sup&gt;</th>
<th>Attitudes&lt;sup&gt;b&lt;/sup&gt;</th>
<th>Behavioral intentions&lt;sup&gt;c&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean d</td>
<td>SE</td>
<td>SD</td>
</tr>
<tr>
<td>All studies (N=79)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Contact in person</td>
<td>.516**</td>
<td>.060</td>
<td>.473</td>
</tr>
<tr>
<td>Contact by video</td>
<td>.155*</td>
<td>.048</td>
<td>.211</td>
</tr>
<tr>
<td>Studies focusing on</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>adolescents (N=19)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td>.392***</td>
<td>.056</td>
<td>.262</td>
</tr>
<tr>
<td>Contact</td>
<td>.244***</td>
<td>.061</td>
<td>.177</td>
</tr>
<tr>
<td>In person</td>
<td>.401***</td>
<td>.090</td>
<td>.338</td>
</tr>
<tr>
<td>By video</td>
<td>.166**</td>
<td>.060</td>
<td>.155</td>
</tr>
</tbody>
</table>

<sup>a</sup> d, adjusted mean effect size; SE, standard error of the mean effect size; SD, standard deviation of the mean effect size; K, number of effect sizes; Qw, homogeneity

<sup>b</sup> Between-groups comparisons: contact approach (all studies), Q=22.10, df=1 and 140, p<.001; education versus contact (studies of adolescents), Q=3.21, df=1 and 145, p<.10; contact approach (studies of adolescents), Q=4.73, df=1 and 67, p<.05

<sup>c</sup> Between-groups comparisons: contact approach (all studies), Q=18.70, df=1 and 77, p<.001; education versus contact (studies of adolescents), Q=4.98, df=1 and 95, p<.05; contact approach (studies of adolescents), Q=1.70, df=1 and 45, p=.33

* p<.05
** p<.01
*** p<.00
The California Schedule of Key Ingredients for Contact-Based Anti-Stigma Programs

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Glen McClintock²
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Michael Gause²
Blythe Buchholz, B.S.¹

¹ Illinois Institute of Technology
² Mental Health Association of San Francisco

Objective: A major public health priority has been to eliminate stigma’s egregious effects on life opportunities for people with mental illnesses. Research shows contact-based anti-stigma programs are among the most effective. Such findings call for clarity to define the components of consumer-directed anti-stigma programs. This paper represents Community Based Participatory Research (CBPR) and the first step of a mixed methods design to describe the active ingredients comprising these kinds of programs.

Methods: CBPR investigators developed an interview guide and subsequently facilitated four focus groups to identify key components. Participants included anti-stigma experts with lived experience. Using grounded theory, two independent raters identified 641 discrete themes. Two additional coders then sorted themes into constructs representing key ingredients of contact-based programs. Coders agreed upon 198 constructs then grouped them into a hierarchical model of key ingredients in consumer-directed stigma change.

Results: Five criteria represent indicators of successful consumer-directed programs: (1) program design, factors necessary for trained presenters to facilitate programs; (2) targeting, tailored presentation congruent with target’s goal; (3) staffing, facilitators and leadership are diverse people with lived experience (4) messaging, presentation discusses struggles and recovery from mental health challenges; and (5) follow-up and evaluation, assessment of sustained audience change.

Conclusions and Future Directions: This study identified key ingredients of consumer-directed anti-stigma programs. Part two of the mixed methods design, a quantitative cross-validation study will yield a sound fidelity measure.
The California Schedule of Key Ingredients for Contact-Based Anti-Stigma Programs

The public stigma of mental illnesses has broad and egregious effects on life opportunities of people with mental illnesses. Social psychologists distinguish elements of public stigma including stereotypes (beliefs about a group like people with mental illnesses are dangerous), prejudice (agreement with the stereotype leading to negative emotions such as fear or anger), and discrimination (the resulting loss of opportunity) (Corrigan, 2005). Discrimination is often considered its most egregious result leading to, for example, employers who might not hire people labeled with mental illnesses (Brohan et al., 2012; Ren, Paetzold, & Colella, 2008; Tsang et al., 2007), landlords not renting to them (Corrigan et al., 2003; Wahl, 1999), and primary care providers offering less quality services (Desai, Stefanovics, & Rosenheck, 2005; Druss, Zhao, von Esenwein, Morrato, & Marcus, 2011). Hence, both policy makers and advocates have made elimination of stigma, and the prejudice and discrimination they create, a major public health priority. A recent meta-analysis summarized the research literature on anti-stigma strategies, sorting these approaches into education (defined as challenging myths with the facts about mental illnesses) and contact (planned exchanges between people with lived experience and the “public”) (Corrigan, Morris, Michaels, Rafacz, & Rüsch, 2012). Results from research on more than 38,000 research subjects showed participants in both education and contact programs showed significant reductions in stigmatizing attitudes and proxies of discriminatory behavior. Effect sizes for contact programs were significantly larger than education, sometimes by threefold or more. These findings represent immediate post-test effects only because few studies examined stigma change at follow-up. One randomized controlled trial showed benefits found at post-test for research participants in an education condition returned to baseline at follow-up, while contact participants continued to show significant reductions in stigma (Corrigan et al., 2001). Combined, these studies suggest contact might yield the greatest effects for sustained stigma change.

Consistency of these findings has engendered a call for contact-based interventions; consumer-directed programs in government-led stigma reduction programs of Canada (Canadian Mental Health Commission), Australia (beyondblue), the UK (Time to Change), and the U.S. (SAMHSA, the Department of Veterans Affairs, the Department of Defense). This call begs a question: what exactly are consumer-directed anti-stigma programs? If, for example, these kinds of programs were to be designated an evidence-based practice (EBP), what would programs need to do to demonstrate they are implementing effective practices? Services researchers often address questions like these by developing fidelity measures that represent key ingredients comprising an EBP. For example, researchers have developed and tested fidelity measures for SAMHSA EBPs such as supported employment (Bond, Campbell, & Drake, 2012; Catty et al., 2008) and assertive community treatment (McHugo et al., 2007; Monroe-DeVita, Teague, & Moser, 2011). The key ingredients that comprise fidelity measures often emerge from careful dissection of the treatment manuals from which EBP assertions arise.

Structured programs and manuals have emerged reflecting consumer-directed anti-stigma efforts (Corrigan, 2011; Sartorius, 2006). For example SAMHSA recently released an evidence-based toolkit focusing on effectiveness and fidelity of consumer-operated services meant to promote empowerment and self-determination among people with lived experience (SAMHSA, 2011). Despite this and the many existing stigma reduction programs which feature consumers as core messengers, there is no consensus about consumer-directed stigma reduction services that reflect the same kind of “state-of-the-art” manual as other psychosocial EBPs. Presumed in this discussion is a definition of “consumer-directed” per se. We defined it as programs developed, operated, and managed by people with lived experience for focus group participants. We realize, however, that this definition itself would benefit from further elaboration, hence, an additional benefit of this qualitative research.

Consensus is an especially important idea because consumer-directed contact programs emerged relatively spontaneously out of the grassroots efforts of people with lived experience from diverse backgrounds. Hence, any attempt to define principles and practices that describe consumer-directed anti-stigma programs need to represent a consensus fully informed by this group. Given this, community based participatory research (CBPR) is essential to this effort. This paper represents CBPR and the first steps of a mixed methods design to describe the active ingredients that comprise contact-based, consumer-directed, anti-stigma programs.
Methods

In 2004, California’s voter initiated Proposition 63 established the Mental Health Services Act (MHSA), which imposed a 1% tax on personal annual income in excess of $1 million as a source of new monies for mental health services and initiatives. The MHSA identified six priority areas including “Prevention and Early Intervention” intended to, in part, fund programs that reduce the stigma and discrimination associated with mental illnesses through local and statewide projects. Two projects were awarded which established the funding base for the California Center for Dignity, Recovery, and Stigma Elimination (California Center), a partnership of consumer-operated programs from across the state under the direction of the Mental Health Association of San Francisco. Through these statewide grants, the California Center was charged to develop and promote contact-based, anti-stigma programs. To do that, the California Center embarked on a CBPR program to identify key ingredients of these kinds of programs.

The five consumer directors of the California Center joined with two investigators to develop an interview guide for focus groups comprised of anti-stigma experts with lived experience who tell their stories of recovery, what seems to be central to contact-based programs. Multiple iterations led to a guide with five question areas: (1) What exactly does stigma mean to you? We began with this question so participants could consensually develop their own concept of stigma rather than being driven by a preconceived notion from us. (2) What does it mean to change stigma? (3) What are characteristics of good stigma change programs? (4) What is the role of diversity in changing stigma? (5) What resources are needed to sustain these programs? California Center leaders also strategized ways to recruit grassroots advocates and practice experts that represent the diversity of Californians in terms of race, ethnicity, region, and population setting (e.g., urban, rural, border). In short, they used a snowball strategy within their network to identify participants from Los Angeles, Sacramento, San Diego and San Francisco; focus group members were consumer advocates from the local area, people with lived experience who had previously conducted anti-stigma programs. Focus groups were conducted by a single facilitator with extensive experience doing this work (PWC or JL) and lasted 90 minutes to two hours. Table 1 describes demographics of participants in each group.

Notes were taken and overall themes were then obtained using a grounded theory approach to qualitative analysis (Strauss & Corbin, 1998). Open coding by two independent raters yielded 641 discrete themes suggesting saturation was reached after four focus groups. “Discrete” was defined as a single idea or concept typically framed as a self-contained sentence or phrase. A second set of coders then sorted the 641 themes into common constructs meant to represent key ingredients in contact-based stigma reduction programs using a grounded theory approach. The two coders consensually agreed upon 198 constructs of stigma and consumer-directed stigma change.

Results

Table 2 summarizes a menu of key ingredients comprising contact-based anti-stigma programs; 31 ingredients were organized into five criterion sets. Program design is the logistics and operational concerns necessary to implement the program. Targeting refers to identifiable and discrete groups for whom individual presentations are crafted. Messaging are definitions regarding who is able to present and sustain the program. Follow-up and evaluation are efforts after
initial interaction meant to cement anti-stigma efforts as well as examine their impact. We develop each area more fully below.

--- Insert Table 2 about here. ---

**Program design.** Advocate experts in focus groups believed effective contact-based anti-stigma programs are provided face-to-face in the target’s setting, which requires presenters to travel to that setting. Presenters should be matched to the target audience; e.g., if the audience is largely African American, presenters should be African American. The program should have fact sheets or other information summarizing important take-home messages that can be disseminated at the meeting. This information can be augmented with web resources (such as a website or facebook page) which also should be shared at the interaction. Advocates participating in the study believed there were optimal sizes to group interactions; not too big (over 50) so impact of the interaction is diluted, nor too small (less than 5), unintentionally denigrating the importance of the exchange. Presenters need to participate in a training program and meet some standard for competence before going into the field. Presentations need to include planned discussion; this kind of active interchange often leads to the greatest stigma change. Audience discussion might include question and answers or “me too” opportunities where audience members discuss their experiences with recovery and stigma. Presenters should be compensated for their work.

**Targeting.** Presentations need to be strategically directed towards individuals or groups who, by virtue of societal role, are in positions of power vis-à-vis people with mental illnesses. Table 3 is a list of twelve targetable groups generated by the focus groups (in alphabetical order); they include groups defined in terms of their functional (e.g., hiring people, renting to them, enforcing the law, guaranteeing government entitlements, providing health care, and examining military service) versus affiliative relationships (family, local communities, faith-based, and cultural groups). An additional target is entertainment and news enterprises and the potential harm (perpetuating stereotypes) and benefits (spreading ideas of recovery) media promotes. Alongside each group in Table 3 are corresponding goals; usually written in the affirmative, the goals become the aims of individual anti-stigma presentations. Under functional relationships, for example, they include employers seeking to increase hiring and providing reasonable accommodations, landlords offering better properties and opening units to peer supports, and health care providers fostering shared decision making and integrated care. In the affiliative area, goals might include accepting family members with mental illnesses, greater inclusion in church communities, or fighting pernicious values like Not in My Back Yard (NIMBY).

--- Insert Table 3 about here. ---

Given notions of target, focus groups identified five key ingredients. Specific groups and corresponding goals need to be identified. Presenters must reach out to target groups and join with them in a needs assessment; e.g., what might exactly be changed among employers who attend a presentation with *Rotary International*. The needs assessment is used to develop an explicit stigma change plan prior to engaging the targeted group. Leadership of the target group needs to be actively incorporated into the presentation.

**Staffing.** Presenters are people with lived experience. “Lived experience” was difficult to define; e.g., what experiences are necessary to be considered among those with serious mental illnesses. However, focus group participants agreed presenters should be in recovery using a process definition of the experience: namely, the person is hopeful and goal-oriented despite current or past symptoms and disabilities. Not only should presenters be people with lived experience, but so should program leadership: the people charged with program coordination as well as a steering committee. Focus group members noted that presentations may be stressful and therefore recommended mutual support opportunities among presenters. These should be regularly scheduled exchanges where presenters can problem solve difficulties with past presentations as well as share successes. Presenters need to be diverse, culturally and in terms of gender, sexual orientation, and other important life conditions.
Messaging. The heart of the presentation is the story and its message. Focus group participants noted that presenters discuss their struggles or “on the way down” stories describing the depth of their illness and disabilities. This is necessary to “qualify,” i.e., to prove to the targeted group that, despite looking “real good to you all today,” the presenter has indeed been challenged by serious mental illnesses. More importantly, messages need to include “on the way up” stories: discussing strengths and successes indicative of recovery and resilience. The message needs to include an explicit, affirming goal statement specifying what is hoped to be achieved through the presentation. “We want from you employers not only the chance to be hired, but the kind of reasonable accommodations that will help me be a strong worker for you.” Messages need to be respectful to the cultural diversity of the targeted audience.

Follow-up and evaluation. Focus group members said subsequent interactions are important to maintaining effects. They believed this is best done by presenters ending first engagements with discussions of specific actions that targets intend to pursue going forward. Presenters should then contact targets after the original presentation, in part as a booster to the original message and in part to determine status of actions. The original needs assessment serves as goals for a program evaluation. Presenters should collect some kind of data that reflect attainment of the goals immediately after the presentation and at one-month follow-up. Finally, program leadership should sit down with presenters regularly and debrief: review processes and outcomes to identify success and shortfalls as a way to further adapt the program for future efforts.

Discussion

Information obtained from four focus groups of mental health advocates with lived experience yielded a model of stigma and its solutions. In turn, review of the model and its components led to a menu of key ingredients to consumer-directed anti-stigma programs. These ingredients were organized into five sets. (1) Program design included the operational concerns necessary for presenters and presentations to conduct effective programs. (2) Anti-stigma efforts need to be targeted: namely, presenters should consider the role of program recipients in the lives of people with serious mental illnesses. This consideration typically leads to some sense of goal: e.g., as a result of the specific anti-stigma effort, faith based communities are more welcoming to peers with serious mental illnesses. (3) Staff and leadership need to be people with lived experience in recovery. (4) Messages need to combine the personal challenges of symptoms and disabilities, the experience of recovery, the impact of stigma, and a call for affirmative efforts moving forward. (5) Anti-stigma efforts should not stop with single presentations. Presenters and targets need to plan how to move forward and what efforts they will implement to evaluate progress.

Qualitative methods are useful for generating elements of a model of a phenomenon and fruitful when seeking the perspective of a subgroup of the population: advocates with lived experience. This study was strong because it represented the collective feedback of a diverse group of advocates with lived experience who have had previous expertise in consumer-directed stigma change. Data are limited, however, because of the relatively small sample size representing perspectives solely of Californians with lived experience. Qualitative data from elsewhere might yield additional ingredients. For example, one reviewer of the first draft of this paper noted qualifications beyond personal experiences of the presenter were not addressed. The reviewer said that considerable time is often needed for people to become skilled to speak in public about their recovery paths. Moreover, findings from this first wave of qualitative work more accurately represent perceptions of ingredients than key ingredients per se. The kind of information that emerges from qualitative efforts needs to be cross-validated in subsequent quantitative research, a stage of research in which our group is currently engaged. We have recruited 100 advocates with lived experience to evaluate the key ingredients in terms of their importance for consumer-directed stigma change.

Stigma is a multi-faceted construct. As shown in this study and in previous reviews of the literature (Link & Phelan, 2001), the prejudice and discrimination experienced by people with mental illnesses includes public stigma, self-stigma, and label avoidance (deciding not to seek mental health services when distressed in order to avoid stigmatizing labels). Hence, a second goal of the cross-validation is to determine whether individual ingredients are important for one type of stigma change compared to another. For
example, as laid out in Table 2, messages including, “empowered person who is proud of attaining goals,” might have greater impact on self-stigma. This is an important distinction given recent concerns in the literature that suggest efforts to diminish one form of stigma might actually worsen another (Corrigan & Fong, 2012). For example, many government-based anti-stigma programs have tried to diminish label avoidance and promote care seeking by framing individual mental illnesses as “treatable brain disorders.” One unintended consequence of this approach is to exacerbate notions that people with mental illnesses are fundamentally different from the rest of the population, a difference that may exacerbate public prejudice (“People with mental illnesses aren’t able to work as well as everyone else because they’re sick.”) and subsequent discrimination (“Therefore, I won’t hire Harry because of his mental illness.”).

Ultimately, ingredients in Table 2 might be grist for a fidelity measure. Subsequent work will need to specify anchors for each ingredient: the degree to which specific ingredients are demonstrated. For example: one element under Staffing in Table 2 stipulates: “presenter is person with lived experience who discloses MH challenges, treatment, and recovery.” What percent of presenters are necessary to make this criterion? Fidelity measures often frame this issue on a continuum where programs, for example, that have 80% of presenters with lived experience are scored more positively than those with only 20%. This kind of evaluation is useful for programs because it suggests directions for change in trying to improve impact. It is beneficial for funders to identify programs that more closely parallel what is known to be effective consumer-directed stigma change programs. Both assertions assume we know which, among individual ingredients, are key for effective change. Additional research needs to validate this assertion. It needs to demonstrate, for example, that programs with greater ratio of presenters with lived experience yield more significant stigma change in target groups.

There is an irony in attempts to document key ingredients and develop fidelity measures. Consumer-based stigma strategies emerged out of grassroots efforts by disenfranchised people with lived experience to impact an unjust community. Hence, describing effective stigma change was in the hands of peer advocates. Translating consumer-directed stigma change in an evidence-based practice framework with both key ingredients and fidelity measures puts this grassroots spirit at risk. Now, agents separate from the community of consumers and survivors may be in position to evaluate whether an individual anti-stigma program, even a program with a long and seemingly revered history, might not be meeting the mark of evidence. This is a tension between a movement and evaluation of the movement that is not easily resolved in the guise of scientific methods or principles. Since in this approach consumers are the agents/messengers of the change intervention, an empowering model of evaluation of stigma-reduction programs should be, ideally, led, overseen and developed by people with lived experience. The current research has embraced this principle by design, placing the highest value on that experience as the fund of expertise for grounding evidence-basis and effectiveness in the context of real-world programs for stigma-change.
References


Table 1. Demographics of the four focus groups in California.

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<tr>
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<td><strong>Race/Ethnicity</strong></td>
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<td>African American</td>
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<td>Asian/PI</td>
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<td>Caucasian</td>
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<td>10</td>
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<td>Latino</td>
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<tr>
<td>Native American</td>
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<td><strong>Table 2. Key ingredients in consumer-directed anti-stigma programs.</strong></td>
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<tr>
<td><strong>1. PROGRAM DESIGN:</strong> Facilitation of program presentation by trained presenters.</td>
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<tr>
<td>- Programs presented face to face</td>
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<tr>
<td>- Presenters travel to targets’ setting</td>
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<tr>
<td>- Presenters matched with and reflective of target audience</td>
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<tr>
<td>- Presentation includes written materials for more information</td>
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<tr>
<td>- Target group size on average is optimal</td>
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<tr>
<td>- Presentation provides web address for more information</td>
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<tr>
<td>- Uses or directs to corresponding e-media for interactive discussion/exchange (e.g., Facebook)</td>
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<tr>
<td>- Program has structured training for presenters</td>
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<tr>
<td>- Presentation included facilitated audience discussion (Q&amp;A and/or “me too”) and/or activities</td>
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<tr>
<td>- Presenters compensated for their work</td>
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<tr>
<td><strong>2. TARGETING:</strong> Tailored presentation supported and congruent with target’s goal.</td>
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<tr>
<td>- Specific group identified (e.g., landlords, employers, primary care providers)</td>
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<tr>
<td>- Affirming goal corresponds with group (e.g., small business owners hire people)</td>
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<tr>
<td>- Needs assessment completed with targets to ensure program presenters meet target’s goals</td>
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<tr>
<td>- Develop partnered plan with target representatives</td>
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<tr>
<td>- Partnership established with target leadership to publicly support efforts</td>
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<tr>
<td><strong>3. STAFFING:</strong> Program staff and leadership includes diverse people with lived experience.</td>
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<tr>
<td>- Presenter is person with lived experience who discloses MH challenges, treatment, and recovery</td>
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<tr>
<td>- Program coordinator is person with lived experience who discloses those challenges</td>
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<tr>
<td>- Program led by steering committee of people with lived experience who disclose</td>
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<tr>
<td>- Program has mutual support program for presenters</td>
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<tr>
<td>- Presenters reflect diversity of community they serve in terms of ethnicity, language and/or faith</td>
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<tr>
<td>- Presenters reflect diversity of community they serve for gender, age, and or sexual orientation</td>
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<td><strong>4. MESSAGING:</strong> Targeted presentation discusses struggles and recovery from mental health challenges.</td>
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<tr>
<td>- Message includes struggles with lived experience: the person is/was challenged by mental illness</td>
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<tr>
<td>- Message includes on-the-way-up story discussing strengths and recovery. The person is resilient</td>
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<td>- Message includes empowered person who is proud of attaining goals beyond their mental health</td>
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<tr>
<td>- Message includes affirming goal statement (e.g., people with mental illnesses make good employees)</td>
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<tr>
<td>- Message is respectful of and relevant to diversity issues of target group</td>
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<td><strong>5. FOLLOW-UP &amp; EVALUATION:</strong> Assessment of sustained audience change.</td>
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<td>- Post presentation follow-up actions discussed with targets</td>
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<td>- Post presentation follow-up contact with targets conducted</td>
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<tr>
<td>- Post-presentation evaluation of goal attainment</td>
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<tr>
<td>- Program debriefing/quality improvement discussion conducted with program presenters</td>
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<tr>
<td>- At least 1-month follow-up evaluation conducted</td>
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<tr>
<td>GROUPS</td>
<td>CORRESPONDING GOALS</td>
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<td>--------------------------------------------</td>
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<td>Community</td>
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<td>Neighborhood members</td>
<td>Decrease NIMBY</td>
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<td>Peers</td>
<td>Social acceptance of mental illnesses</td>
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<td>Elders</td>
<td>Empowerment</td>
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<td>Service clubs (fraternal, military)</td>
<td>Resilience</td>
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<td>Education System</td>
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<td>School/college instructors and administrators</td>
<td>Classroom accommodations</td>
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<td>Classmates</td>
<td>Acceptance and support</td>
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<td>Employers</td>
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<tr>
<td>Small business owners</td>
<td>Increase hiring and reasonable accommodations</td>
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<tr>
<td>Corporations</td>
<td>Promote understanding and acceptance</td>
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<td>HR representatives</td>
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<td>Coworkers</td>
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<td>Ethnic/Cultural Groups</td>
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<tr>
<td>Racial and ethnic groups</td>
<td>Promote mental health services</td>
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<td>Non-English speaking groups</td>
<td>Advocacy for personal/group rights</td>
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<td>LGBTQ community</td>
<td>Service navigation</td>
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<tr>
<td>Families</td>
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<td>Immediate family; Spouses</td>
<td>Accepting family member with mental illnesses</td>
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<td>Faith-Based Institutions</td>
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<td>Faith leaders; Congregation members</td>
<td>Greater inclusion in the community</td>
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<td>Government Related</td>
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<tr>
<td>Legislative officials: legislatures, city councils</td>
<td>Support greater resources to mental health</td>
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<td>town hall meetings</td>
<td>Provision of entitlements</td>
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<td>Foster care; Child protective services</td>
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<td>Administrative officials: public aide offices</td>
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<td>Department of Motor Vehicles</td>
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<td>Health Care</td>
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<td>Physical and mental healthcare</td>
<td>Shared decision making</td>
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<td>Nursing homes; Senior centers</td>
<td>Integrated care</td>
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<td>Nurses</td>
<td>Promotion of recovery</td>
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<td>Providers; Line/Intake staff</td>
<td>Policy entitlements</td>
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<td>Students</td>
<td>Accommodations</td>
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<td>Insurers</td>
<td>Service seeking</td>
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<td>Consumers</td>
<td>Engagement</td>
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<td>Housing</td>
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<td>Landlords</td>
<td>Increase rentals and reasonable accommodations</td>
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<td>Real estate agents</td>
<td>Increase rentals, sales, and appropriate financing</td>
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<td>Law Enforcement</td>
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<td>Police officers</td>
<td>More temperate responses</td>
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<td>Juvenile justice officers</td>
<td>Procedural Justice</td>
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<td>Court officials</td>
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<td>Probation officers</td>
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<td>Media</td>
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<tr>
<td>News</td>
<td>Promote positive images</td>
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<tr>
<td>Entertainment media (print, radio, digital)</td>
<td>Stop negative images</td>
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<td>Military</td>
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<td>Officers</td>
<td>Accommodations</td>
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<tr>
<td>Enlisted personnel</td>
<td>Awareness of social programs and resources</td>
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Reducing Self-Stigma by Coming Out Proud

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Abstract

Self-stigma has a pernicious effect on the lives of people with mental illness. Contrary to a medical view, identifying with one’s mental illness and publicly disclosing it may promote empowerment and reduce self-stigma. This paper reviews the extensive research that supports this assertion and then segues into a program that might diminish stigma’s effect by helping some people to come out with their experiences with mental illness, treatment, and recovery. The program includes weighing costs and benefits of disclosure in order to make a decision about whether or not to come out, different strategies for coming out once the decision is made, and benefits of peer support through the disclosure process. Challenges which this kind of program poses for public health research are reviewed.
Reducing Self-Stigma by Coming Out Proud

People with mental illness who internalize stigma often experience significant loss in self-esteem and self-efficacy, which may interfere with the course of their illness, achievement of personal goals, and participation in evidence-based services. This is called self-stigma. An interesting empirical question examines the role of identity and disclosure on self-stigma. One might think, consistent with a medical perspective attempting to “eliminate a disease,” that people should distance themselves from a mental illness and that disclosure may be harmful to self-esteem and self-efficacy. However, research shows that sharing one’s experiences with mental illness and corresponding treatments can be empowering and may actually enhance self-esteem for some people. We seek to make sense of these seemingly contrary circumstances here in the process offering theoretical ground for the essential public health goal of the paper; namely, to inform the advocacy community about how it might avail this insight to develop an effective approach to self-stigma change. The GLBTQ community calls this coming out: announcing to the world one’s sexual orientation proudly in order to assert control over one’s life. Although the experiences of GLBTQ individuals and people with mental illness are not equal, there are sufficient parallels to transpose research and theory from the coming out literature to the self-stigma reduction goals of people with mental illness. In the process, we will summarize discrete practices which public health advocates might adopt to promote coming out proud.

The Problem of Self-Stigma

Sociologists since George Herbert Mead framed deviance and stigma as social constructions; rather than being inherent, the meaning of behavior is subject to interpretation and definition bounded by the constraints of language and symbol. This has been further described in terms of identity -- that conceptualization of self meant to foster a sense of personal esteem and efficacy -- and identity threat, the harm that occurs when one’s sense of self is challenged by association with a stigmatized group. Identity threat appraisals have pernicious effects on emotional well-being (increased anxiety and vigilance) and corresponding health. Social psychologists have further described stigma in terms of cognitive structures, perspectives that are especially useful for making sense of identity threat and self-stigma in people with mental illness: stereotypes (usually negative beliefs about a group: “people with mental illness are dangerous”), prejudice (subsequent endorsement of these beliefs leading to negative emotional evaluation: “that’s right; they’re dangerous and I’m afraid of them”), and discrimination (the behavioral response to prejudice: “and because I am afraid of them, I am not going to hire them”).

Some people with mental illness who internalize these stereotypes suffer significant blows to self-esteem and self-efficacy which may undermine pursuit of goals related to independent living including employment. This has been called the “why try” effect. “Why try seek out a job? I am not worthy of it.” “Why attempt to live on my own? I do not have the skills to manage my own home.” “Why try” is a variant of what Link et al called modified labeling theory, when people perceive devaluation, they avoid situations where public disrespect is anticipated. Finally, self-stigma can undermine participation in services that might diminish a mental illness and its corresponding challenges.

Approaches to Addressing Self-Stigma in Mental Illness

Programs have been developed to reduce the pernicious and insidious effects of the self-stigma of mental illness. A recent comprehensive review of the literature yielded fourteen studies that have tested these kinds of programs. Psychoeducational programs were most common in which participants were taught facts that disputed stereotypes of mental illness. The educational experience was often augmented by participants sharing their own experience with the prejudice of others and its internalization. A second approach to self-stigma reduction incorporated Cognitive Behavior Therapy (CBT), framing self-stigma as irrational self-statements which the person seeks to strategically challenge by collecting feedback from others. These challenges lead to counters -- pithy statements people might use next time they catch themselves self-stigmatizing. More recently, a variant of CBT -- Acceptance and Commitment Therapy -- was used to address self-stigma. This approach incorporated mindfulness strategies to promote self-esteem among group participants. Another intervention augmented CBT with narrative enhancement, the
sharing of personal stories focusing on themes of hope which contrast with stigmatizing views. Narrative enhancement diminishes stigmatizing effects by helping people experience themselves as entitled and able to engage in meaning making through constructing a personally meaningful story in which one is a protagonist.

**Identity and Disclosure**

In summarizing social psychological theory about ways to challenge the identity threat that results from stigma, Major and O’Brien pointed to an additional approach to resolving self-stigma. Individuals who identify with their stigmatized group may report less stress due to prejudice and better self-esteem, a result found in African Americans, older adults, women, and gay men and lesbians. The last group, which we more broadly construe as GLBTQ, is especially relevant for understanding the experiences of identity and mental illness because GLBTQ and mental illness are conditions Goffman considered marked by “discreditable” stigma. Namely, indication of group membership is not readily obvious to the public (compared, for example, to skin color for ethnicity or body type for gender). Hence, effects of group identification are influenced by public disclosure of membership in the stigmatized group. Keeping secret and suppressing such important aspects of one’s identity as his or her sexual orientation have egregious effects -- what Smart and Wegner call “private hell” -- with harmful impact on mental health, physical health, relationships, employment, and well-being. Strategic disclosure of one’s “closet secrets” not only seems to diminish these hurtful effects but often leads to a sense of personal empowerment and improved self-esteem.

We believe the GLBTQ experience is a useful metaphor for discussion of mental illness identity and disclosure, but, in the process, do not mean to repeat previous mistakes of psychiatry and the DSM by framing GLBTQ as mental illness. How are the two experiences similar? The public cannot easily tell people are gay or mentally ill just by looking at them. Naïve psychological notions might suggest that homosexuality (or mental illness) distinguishes a unique category from the rest of the population (straights or non-mentally ill), a kind of duality that accentuates the “we versus they” qualities that augment stigma. This can be false. Although many people characterize themselves as either gay or straight, there are others who self-identify as heterosexuals and have had gay or lesbian experiences, or are bisexual altogether. Similarly, the boundary between mental illness and “normal” is gray. Many symptoms of mental illness including depression and anxiety are quite common. Finally, both groups have been stigmatized because of society-wide misperceptions. In earlier times, homosexuality and mental illness were viewed in moral terms. Homosexuality represented a volitional decision to opt for a sinful lifestyle. Mental illness embodied the demon-possessed individual who did not have sufficient moral backbone to hold off satan. The Nineteenth and Twentieth Centuries replaced religious models with views that medicalized the conditions. The DSM-I, for example, listed homosexuality among the sociopathic personality disturbances. At the same time, most of what we consider to be major mental illnesses -- schizophrenia, bipolar disorder, major depression -- have been defined as medical conditions.

Although a useful metaphor, there is still a difference between the experience of GLBTQ and people with serious mental illness relevant to coming out. Namely, unlike GLBTQ, people with mental illness are challenged by symptoms and disabilities that interfere with life opportunities. Hence, they must sort out barriers to life goals based on stigma versus disabilities; current symptoms will likely impact coming out decisions and activity.

In order to escape the opprobrium of prejudice and discrimination, people might seek to deny self-perceptions consistent with a stigmatized role. For example, people with sexual orientations that differ from the majority might distance themselves from thoughts and behaviors consistent with their orientation in order to control pejorative self-statements; e.g., “I am morally weak because I am attracted to people of the same gender.” A prescription towards color blindness in the 60’s represented this erroneous value; people of color should ignore their ethnic difference in preference for a world without color boundaries. The Black Power movement that emerged in that decade was in reaction to this naïve view; instead people should embrace the wondrous diversity of their African heritage with pride. Similarly, research fairly consistently shows GLBTQ who accept and hold close their sexual orientation, often publicly, experience
not only less self-stigma, but also greater self-esteem, health and wellness, relationship satisfaction, and personal achievement.

Identity and Mental Illness

There may be an intriguing contradiction that seems to challenge facile extrapolation of this view of identity development to the experiences of people with mental illness. Research seems to support the health value of avoiding a mental illness identity. Research has described the deleterious effect of assuming a sick patient role suggestive of worse prognosis and greater pessimism. Confounding this in especially serious mental illnesses like schizophrenia is the concern that a cogent sense of self may be disrupted by cognitive dysfunctions including poor insight into one’s illness. This would seem to imply identity as a person with mental illness is to be avoided. Add to this the impact of identity threat on people with mental illness. Research has validated Major and Obrien’s model on people with mental illness, showing identity threat appraisals corresponded with lower self-esteem.

The relationship between identity and self-stigma is a bit more complex however. An important study by Lysaker and colleagues showed the effects of illness identity are influenced by perceived legitimacy of mental illness stigma. Those who identified with mental illness but also embraced the stigma of their disorder were likely to report less hope and diminished self-esteem. Conversely, those whose sense of self prominently included their mental illness and rejected the stigma of mental illness not only showed more hope and better self-esteem, but enhanced social functioning as well. Hence, identity with one’s mental illness does not automatically lead to more stress; it is the perceived legitimacy of the stigma that threatens one’s identity that harms one’s emotional health. Qualitative research by Davidson and others explained this in terms of the transformative process of constructing a new sense of self. Roe described the evolution from patiendh to personhood as not necessarily a rejection of one’s mental illness as much as an integration of its central experiences into the whole of a person’s self-image. The ever-emerging conversation about recovery and capabilities seeks to move description beyond a medical perspective of recovery as an end state -- remission of symptoms and overcoming of disabilities. These are only one aspect of a definition of recovery which research has shown to include a sense of hope, goal attainment, and community.

Pride and Mental Illness Identity

What about qualifying the identity experience with pride leading to notions of coming out proud? Would we call the mental illness, or “surviving” the mental illness, the source of pride? Pride and identity have been understood in multi-factorial models that, among other things, distinguish accomplishment from being. On one hand, people experience pride in achieving a standard recognized by their culture (e.g., a medal for the long distance runner or a college degree for the person challenged by psychiatric disabilities) or set by themselves (e.g., a personal best running time or meeting a course deadline when experiencing a recurrence of depression). In these examples, it seems to be overcoming the challenges of mental illness that lead to identity pride, an experience not to be minimized. But, there may be a downside to this view, one that recapitulates the medical view of recovery; namely, that pride is only achieved when symptoms are remitted and disabilities resolved. Alternatively, there may be benefit from identity as a person attains some sense of agency along with symptoms and disabilities; i.e., decision and self-determination in the ground of mental illness is an identity that yields self-esteem and self-worth about which a person might be proud.

In this light, pride emerges from a sense of who one is. Ethnic pride is a clear example here: “I am African American” does not suggest any accomplishment per se but rather satisfaction at the recognition of one’s heritage, an additional answer to the person’s search to answer, “Who am I?” We would argue that this latter phenomenon explains mental illness as an identity in which a person might be proud. Namely, the recognition that, for some people “I am a person with mental illness” defines much of their daily experience. This kind of identity promotes authenticity, a recognition of one’s internal conceptualizations in the face of an imposing world. While authenticity and agency are concepts that emerged from existential philosophy and psychology, recent social scientists have been able to apply it to empirical models of sexual orientation, organizations, and ethnicity. Operationalizing authenticity, for example, in a tripartite model that includes self-alienation, authentic living, and accepting external influence. A scale...
measuring this factor model was shown to predict self-esteem and aspects of well-being. Authentic people have pride in their authenticity.

Group identification, defined as feelings of strong ties to a socially defined collection of people, has been shown to diminish the effects of stigma on the person with mental illness. One study found people with mental illness who more highly identified with the “group” were less likely to experience harm to self-esteem or self-efficacy as a result of internalized stigma. A second study showed strong group identification was associated both with the appraisal of stigma as being potentially more harmful and with more perceived resources to cope with this threat. This means that identifying with the group of people with mental illness can both expose the individual to the risk of being discriminated against as a member of that group (the downsides of disclosure discussed in this paper) and offer sources of support to cope with discrimination. Considering both costs and benefits to coming out is important and reviewed more fully below.

Disclosure of Mental Illness Identity

If some kind of mental illness identity has potentially positive impact, then like many in the GLBTQ community, disclosure of that identity might yield health and other life benefits. Towards this end, qualitative interviews were conducted with gay men and lesbians to identify specific attitudes and behaviors that comprise costs and benefits of both staying in the closet and coming out with one’s sexual orientation. Findings from the study were then transposed into a quantitative assessment of coming out with mental illness. An exploratory factor analysis of responses provided by 85 people with serious mental illnesses yielded a two factor structure: the benefits of being out (BBO) versus the reasons for staying in. BBO was shown to be a protective factor against self-stigma’s effects on quality of life. It also seemed to augment a sense of personal empowerment which enhanced well-being. If findings like this are substantiated in other research, coming out proud could have positive effects on the mental and physical health and well-being of people with mental illness.

Coming Out Proud as a Public Health Program

How do public health advocates promote coming out? Morrow developed and tested a group intervention meant to promote coming out among lesbians. It was an ambitious program with ten sessions that addressed issues like costs and benefits of living openly, homophobia communication skills, sexism assertiveness training, and workplace issues. Results of a non-experimental study showed positive gains in disclosure in intervention group participants compared to a control group. Increased disclosure seemed to correspond with lesbian identity development and enhanced personal empowerment. Based on this model, and the research discussed above, a coming out proud program was developed for public health advocates to help people with mental illness address issues of disclosure and identity. It is a three part program that addresses key issues related to disclosure: (1) the weighing of the costs and benefits of coming out; (2) the range of strategic approaches to actually disclosing; and (3) the augmenting effects of peer support. It is more fully discussed here.

Costs and Benefits of Disclosing

There are many benefits to disclosure including enhanced self-esteem and self-efficacy which promote emotional and mental health which in turn may improve physical health and well-being. We provided a list of examples related to coming out at work in Table 1. Disclosing can improve relationships and expectation at work and many social settings. Still, there are costs as well including (also in Table 1) some risk for physical and emotional harm (hate crimes), discrimination, disapproval from others, and self-consciousness. The balance of costs and benefits depends on the individual and the setting (coming out at work probably has a different pattern of costs and benefits compared to coming out among one’s faith community). Hence, only the person can decide for him or herself. Guiding principles of motivational interviewing may be useful to facilitate the decision process: a facilitator expresses empathy with both costs and benefits of the disclosure decision, avoids argumentation with specific responses, and supports self-efficacy that moves the person to positive change.

Strategic Approaches to Disclosure

Insert Table 1 about here. –
Research has shown disclosure is not a simple or solitary process but might be described by a hierarchy of approaches. In an ethnographic study of 146 people with mental illness, Herman\(^\text{114}\) identified five specific ways in which people might disclose; these are summarized in Table 2 along with a brief cost and benefit to each. At the most extreme level, people may stay in the closet -- not come out at all -- through social avoidance. People who are victimized by stigma may choose to not socialize with, live near, or work alongside persons without disabilities. They may opt to live in a therapeutic community, work in a sheltered work environment, or interact with friends in a social club developed for mental illness. We suspect social avoidance \textit{per se} can lead to as many negative effects as positive ones.

There is no need to avoid work or community situations to keep one’s experiences with mental illness private. Many people choose to enter these worlds but not share their experiences with others. Secrecy provides a means to do this. An alternative third version of this is selective disclosure. Some people take a chance and disclose their mental illness to selected co-workers or neighbors. These people are taking a risk, however; those who find out may shun them. However, with this risk comes opportunity. Persons who disclose may find people who are supportive. There are strategies to “test out” whether a person is potentially a good disclosure receiver.

Selective disclosure means there is a group of people with whom private information is disclosed as well as a group from whom this information is kept secret. People who choose \textit{indiscriminant disclosure} abandon secrecy altogether by making no active efforts to try to conceal their mental health history and experiences. Note, however, that the decision to no longer conceal is not the same as telling everyone one’s story. \textit{Broadcasting} one’s experience means educating people about mental illness. This kind of disclosure is much more than dropping one’s guard and throwing away any notion of secret. The goal here is to seek out people to share past history and current experiences with mental illness. People who broadcast foster their sense of power over the experience of mental illness and stigma.

\section*{Disclosing with a Community of Peers}

Many GLBTQ often report affiliating with a community of peers has augmented a proud identity and processes related to disclosure.\(^\text{115}\) In like fashion, peer support may positively facilitate identity and disclosure of one’s mental illness. Research has shown people with serious mental illness who identify with the “mental illness” group were more likely to be attending a peer support program; those participating in peer support programs reported a better quality of life.\(^\text{116}\) Peer support programs provide a range of services including encouragement for those who are just coming out, shared experiences which foster a sense of community within a larger hostile culture, and advocacy efforts to further promote group pride.\(^\text{76, 117-119}\)

Unfortunately, research on the effects of peer programs is a bit sparse. Results of qualitative evaluations showed that participants in these kinds of programs reported improvements in self-reliance and independence; coping skills and knowledge; and feelings of empowerment.\(^\text{117,118}\) Similar findings are just emerging from a multi-site experimental study of peer support programs.\(^\text{120-122}\) The Wellness and Recovery Action Plan (WRAP) is another peer support program that has garnered research support. In one study, WRAP participants showed significant improvements in self-reported symptoms, recovery, hopefulness, self-advocacy, and physical health.\(^\text{123}\) In a second, WRAP led to significant changes in attitudes regarding hope, recovery, and symptom-management skills.\(^\text{124}\) Research of this kind may show the continued beneficial effects of peer support on self-stigma and disclosure.

\section*{Additional Public Health Approaches}

The Coming Out Proud program described here focuses on what the person with psychiatric illness might do about self-stigma. Coming out is facilitated in a community that disdains stigma and endorses affirming attitudes such as recovery and empowerment. In this light, governments and other large advocacy organizations have made tackling the stigma of mental illness a public health priority\(^\text{125}\). Researchers have distinguished these into education programs (contrasting the myths of mental illness with the facts) and contact (facilitating interactions between people with lived experience and the community)\(^\text{126}\). Results of a recent meta-analysis have shown both forms of public stigma change lead to significant improvements but effect sizes for contact based programs are significantly larger and often three times greater.\(^\text{126}\) This is an intriguing irony in this finding. Public health efforts that promote contact will diminish stigma providing a
community that welcomes disclosure. To do this, however, people with lived experience must come out. Resources to support coming out and contact programs are essential in this movement.
<table>
<thead>
<tr>
<th>Benefits</th>
<th>Costs</th>
</tr>
</thead>
<tbody>
<tr>
<td>You don’t have to worry about hiding your mental illness from supervisor or co-workers.</td>
<td>Others may disapprove of your mental illness or your disclosure.</td>
</tr>
<tr>
<td>You can be more open about day-to-day affairs.</td>
<td>Others may gossip about you.</td>
</tr>
<tr>
<td>You can be honest with the supervisor about requesting time off for appointments with mental health providers.</td>
<td>Others may exclude you from work events or cooperative work projects.</td>
</tr>
<tr>
<td>Others may express approval.</td>
<td>You may worry more about what people are thinking about you.</td>
</tr>
<tr>
<td>Others may have similar experiences.</td>
<td>You may worry that others will pity you or question your competence.</td>
</tr>
<tr>
<td></td>
<td>Hierarchy of Approaches to Disclosure</td>
</tr>
<tr>
<td>---</td>
<td>--------------------------------------</td>
</tr>
<tr>
<td>1.</td>
<td>SOCIAL AVOIDANCE: Do not tell anyone. Avoid situations where people might find out about one’s mental illness.</td>
</tr>
<tr>
<td>Benefit:</td>
<td>You don’t encounter people who will unfairly harm you.</td>
</tr>
<tr>
<td>Cost:</td>
<td>You lose the opportunity to meet new people who may possibly be supportive.</td>
</tr>
<tr>
<td>2.</td>
<td>SECRECY: Keep one’s mental illness a secret, but insert self in environments including individuals with and without mental illnesses.</td>
</tr>
<tr>
<td>Benefit:</td>
<td>You don’t have to avoid important settings like work or the community in the process.</td>
</tr>
<tr>
<td>Cost:</td>
<td>Some people feel guilty about keeping secrets.</td>
</tr>
<tr>
<td>3.</td>
<td>SELECTIVE DISCLOSURE: Disclose mental illness to selected individuals (e.g. co-workers, neighbors).</td>
</tr>
<tr>
<td>Benefit:</td>
<td>You find a small group of people who will understand your experiences and provide support.</td>
</tr>
<tr>
<td>Cost:</td>
<td>You may disclose to some people who then hurt you with the information. You may have difficulty keeping track of who knows and who doesn’t.</td>
</tr>
<tr>
<td>4.</td>
<td>INDISCRIMINANT DISCLOSURE: Choose to no longer actively conceal one’s mental illness from anyone in one’s life.</td>
</tr>
<tr>
<td>Benefit:</td>
<td>You don’t worry who knows about your problems. And you are likely to find people who will be supportive.</td>
</tr>
<tr>
<td>Cost:</td>
<td>You may tell people who then hurt you with the information.</td>
</tr>
<tr>
<td>5.</td>
<td>BROADCAST YOUR EXPERIENCE: Actively seek audiences to educate and inform about mental illness through telling one’s story.</td>
</tr>
<tr>
<td>Benefit:</td>
<td>You don’t have to worry who knows about your history of mental illness. You are promoting a personal sense of empowerment in yourself. You are striking a blow against stigma.</td>
</tr>
<tr>
<td>Cost:</td>
<td>You are going to encounter people who may try to hurt you with this information. You are also going to meet people who disapprove of your political statement.</td>
</tr>
</tbody>
</table>
References


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Evolution of public attitudes about mental illness. A systematic review and meta-analysis.

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Running head: Evolution of public attitudes

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Abstract

Objective: To explore whether the increase in knowledge about the biological correlates of mental disorders over the last decades has translated into improved public understanding of mental illness, increased readiness to seek mental health care, and more tolerant attitudes towards mentally ill persons.

Methods: A systematic review of all studies on mental illness related beliefs and attitudes in the general population published before 31/03/2011, examining time-trends of attitudes with a follow up interval of at least two years and using national representative population samples. A sub-sample of methodologically homogeneous studies was further included in a meta-regression analysis of time-trends.

Results: 33 reports on 16 studies on national time-trends met our inclusion criteria, six of which were eligible for a meta-regression analysis. Two major trends emerged: There was a coherent trend to greater mental health literacy, in particular towards a biological model of mental illness, and greater acceptance of professional help for mental health problems. In contrast, however, no changes or even changes to the worse were observed regarding attitudes towards people with mental illness.

Conclusion: Increasing public understanding of the biological correlates of mental illness seems not to result in better social acceptance of persons with mental illness.

Key words: Health literacy, Stigmatization; Trends.
Summations:
- A more biological public understanding of mental illness parallels greater acceptance of professional treatment, including psychiatric medication.
- Social rejection of mentally ill persons remained disturbingly stable over the last twenty years.
- Increasing public literacy about the biological correlates of mental disorders seems no remedy against stigmatization and discrimination of persons with mental illness.

Considerations:
- Time-trend analyses of mental illness related public attitudes have only been conducted in industrialised, first-world countries, and developments in other parts of the world are unknown.
- This review focuses on broad, long-term developments of public attitudes on a national level. The evaluation of anti-stigma and awareness campaigns, frequently accomplished by short-term and local studies, was not the focus of this review.
Introduction

The last decades have witnessed tremendous advancements of our understanding of the biological correlates of mental disorders. Not only has the knowledge of researchers and mental health professionals expanded, but the public, too, has been increasingly exposed to information on symptoms, biochemical and genetic etiological theories, and to the basic argument that mental illnesses are diseases no different from other diseases, amenable to effective medical treatment (1). As part of a widely recognized effort to “enhance public awareness of the benefits to be derived from brain research”(2), the U.S. Congress and President George H.W. Bush designated the 1990s “Decade of the Brain”. An analysis of the portrayal of depression in high circulating magazines in the US and in Canada has shown that indeed depression moved from a problem explained in a variety of ways in the 1980s to a primarily bio-medical phenomenon in the 1990s and 2000s (3). The coverage of the use of neurotechnology for diagnosis or therapy in neuropsychiatric disorders increased between 1995 and 2004 in major US and UK English-language news sources and was generally optimistic (4).

It was hoped that the promulgation of mental illness as a “real” brain disease would challenge the omnipresent stigma attached to mental disorders. Instead of blaming persons with mental illness for their disorders, people endorsing a biological causal model of mental illness might be more inclined to see symptoms of mental illness as a result of biological illness not under voluntary control (5). In turn, more knowledge and less stigma would lead to greater openness about seeking out treatment or staying in treatment. Many anti-stigma initiatives like that launched by the US National Alliance on Mental Illness (NAMI) have thus incorporated a medicalizing view on mental illness, portraying mental disorders explicitly as medical diseases, for example major depression as “a biological, medical illness” (6), or schizophrenia as an illness “like many other medical illnesses such as cancer or diabetes”(7). Taken together, these developments nourished the expectation that people will become more knowledgeable about mental disorders, professional help and psychiatric treatment will be more accepted, negative stereotypes about mentally ill people will diminish, and social acceptance of people with mental illness will improve.

In this review, we look at population studies on public attitudes to find out whether attitudes have indeed developed in the expected direction. Over the last twenty years, many studies have investigated public beliefs about mental disorders, help-seeking and attitudes towards persons with mental illness. Most of these studies are cross-sectional reports on single surveys. To arrive at valid conclusions about attitude changes at population level, studies need to compare responses to identical items at two (or more) time-points, and all surveys analysed within one study need to be based on identical sampling procedures employed in the same population. In this review, we look at such population studies which we identified in a systematic review. Time-trend studies have been conducted in different countries, cover different time-frames, and use a variety of methods to measure public attitudes. In order to find out whether there is a common trend of public attitudes across different countries and time-frames, we selected a sub-group of studies using similar measures. With these studies, we performed a series of meta-regression analyses to identify any supranational trend of public attitudes related to mental illness.

Aims of the study

To find out whether, over the last decades, the general public has become more knowledgeable about mental disorders and more accepting of professional help-seeking, and whether negative stereotypes and social rejection of persons with mental illness have diminished.

Methods

We conducted a systematic review of all representative population-based studies on public attitudes regarding mental disorders and people with mental illness that have appeared until 31st March 2011.
Specifically, we looked for time-trend analyses, i.e. studies that enquire on public attitudes at least at two occasions with identical methodology. Besides reports published in scientific journals or books, we include also documents published online and so-called “grey literature”, i.e. reports not published in commercially available books or journals. To detect all relevant studies, we took a stepwise approach according to the systematic literature review guidelines of the Centre for Reviews and Dissemination (8) and the Cochrane Collaboration (9).

Searching methods

In order to find all studies examining public attitudes regarding mental illness on a population level, we conducted a literature search in the electronic databases Pubmed, PsychINFO and Web of Science, using the terms (“mental illness” OR “mental disorder” OR schizophrenia OR depression OR alcoholism OR "alcohol abuse" OR "alcohol depend*" OR alcoholic OR “anxiety disorder” OR “obsessive compulsive disorder” OR dementia OR “Alzheimer’s disease”) AND (attitudes OR stigma OR “mental health literacy” OR “causal beliefs” OR “causal attributions” OR stereotype OR “social distance”) AND (representative OR population). No restrictions regarding the language of the indexed articles were applied. We expanded this initial search by screening the bibliographies of all relevant reports and by performing electronic searches for further relevant articles by the first author of any identified study. Additionally, we contacted experts in the field of psychiatric attitude research and asked them about any relevant study not published in peer-reviewed journals or other relevant “grey literature” known to them. Finally, based on all reports identified by this procedure, we conducted a full-text search of all reports specifically looking for eligible time-trend analyses of public attitudes and beliefs.

The initial database search was conducted by GS. Two researchers (GS and MCA) then independently screened titles, abstracts and, where appropriate, the full text of all identified reports in order to minimize the possibility of discarding potentially relevant reports. AH and MCA screened bibliographies of all relevant reports and conducted electronic searches for further relevant articles by all first authors. MCA contacted experts in the field of psychiatric attitude research. Finally, the full-text analysis of all previously identified reports was carried out independently by MCA and AH, looking for reports on trend analyses of public beliefs and attitudes about mental illness. At this stage, native speakers were contacted to provide translations of reports if necessary. Disagreement about inclusion of individual reports was resolved by discussion at both stages (screening and full-text analysis for eligibility).

Study selection

We retained all reports on studies that met the following criteria: First, the focus of the study was on the general public. Studies investigating beliefs or attitudes of particular subgroups such as consumers of mental health services, health professionals or students were excluded. Second, in order to avoid selection effects, we only included studies based on representative population samples obtained either by random or quota sampling methods. Third, we included only studies conducted on a national level (as opposed to local surveys) with a follow up interval of at least two years, since we were interested in broad, sustained time trends of public beliefs and attitudes. The methodological quality of included studies was assessed with regard to sample sizes and response rates.

Data extraction and meta-regression analysis

Corresponding to our research question, data on four domains of attitudes were extracted: Information on beliefs about causes and definition of mental disorder, attitudes towards help-seeking, prevalence of negative stereotypes, and social acceptance of persons with mental illness. Study methodology varied considerably: Answer formats comprised open-ended questions, yes/no-answers, and Likert-type scales. Items were phrased using diagnostic labels (“mental illness”, “depression”, “mental health problems”, “day-
to-day stress” etc.), or referring to an unlabelled brief description of a person with a specific disorder, a case-vignette. Among all studies, we identified a group of studies using a coherent methodological approach with unlabelled case-vignettes of either schizophrenia or depression which were appropriate to a meta-regression of time-trends. In these studies, answers to items relevant to this review were elicited with Likert-type scales with anchors such as “agree completely/disagree completely” or “very likely/very unlikely”. All studies collapsed answers on the approval side of the midpoint of the scale into “agree” or “likely”, and this was the outcome entered into our meta-analysis. Two studies reported disagreement with statements on the willingness to engage in several forms of social contact (“desire for social distance”)(10-13). We contacted the authors of these studies who kindly provided the respective results on agreement with these statements (social acceptance). Aim of the meta-regression analysis was to test whether there were significant supranational trends in attitude-change, and to estimate their magnitude. Our systematic review thus yields two types of results for each of the four attitudinal domains: results of a meta-regression analysis of a selection of methodologically homogeneous studies, and a narrative summary of results from other, methodologically heterogeneous studies.

Statistical analyses were performed using STATA/SE software, release 10 (Stata Corporation, College Station, TX, USA). In contrast to common meta-analysis, we focused on the annual change of the attitude of interest (rather than on the overall attitude). Therefore, only studies with at least two time points were selected. The unit of analysis of our meta-regression was the aggregate-level data for one time point of each study, namely the proportion of respondents endorsing the attitude of interest in one survey. To estimate the overall attitude change per year, we used the revised version of the “metareg” command (14), which performs a random effect meta-regression analysis using aggregate-level data. For each attitude, change was adjusted for country (unless stated otherwise), allowing for differing country-specific baselines for any attitude change. All reported P values are 2 sided. For our figures and tables, proportions (values between 0 and 1) were transformed into percent (0-100) in order to be congruent with the reporting of percentages in the single studies. While tables show results of all meta-regressions conducted, figures illustrate those analyses where the estimation of overall attitude change was statistically significant.

In our figures, circles are positioned to depict the time-point and the results of individual surveys, thus representing the units of analysis. Associated surveys conducted in the same population are represented by similar colours. Circle sizes are proportional to sample sizes (and hence the weight) of the respective study. The slope of the regression line represents average change per year across all countries and illustrates thus the core outcome of our meta-regression. The y-axis intercept of the regression line depicts the estimate for the reference category, Germany (West). West Germany was used as the reference category since this study comprised the largest sample, the longest time period (11 years), and started earliest (1990).

Results

Our initial database search identified 7360 potentially relevant documents. Exclusion of duplicates, of documents not dealing with attitudes of the general population, and of documents not based on representative population samples yielded 324 potentially relevant reports, citation-chasing and first-author searches resulted in another 209 reports that met our inclusion criteria. 26 further reports were identified by contacting experts. Thus, the first step of our search strategy yielded in total 559 reports, 102 of which were written in languages other than English. From these 559 reports, we identified 33 reports on 16 national time-trend analyses of beliefs and attitudes about mental illness, covering periods from three to 46 years. Four of these studies originate from the U.S., five from the UK or Scotland, and one each from Australia, Austria, the Netherlands, Poland, New Zealand and East- and West Germany. Studies from Germany reported separately for East- and West Germany. Given that both regions constituted different countries with very different political and social structures until unification in 1990, this separate consideration of attitude changes seemed appropriate. Data from a Scottish study were reported separately for results obtained with a female and a male case-vignette (15), hence in our meta-regression analysis, this study is treated as two separate studies. 11 studies deal with mental illness in general, ten with schizophrenia, seven with
depression and two with other mental disorders. Seven studies (from Australia, Austria, and UK/Scotland) were conducted pre and post anti-stigma campaigns. Six studies (from Australia, Austria, USA, Scotland, and East/West Germany) used case-vignettes and were thus included in our meta-analysis. Except for one study, sample sizes were generally >1000 respondents, but due to splitting of samples in studies examining different conditions or using male/female case-vignettes, sub-sample sizes varied from 230 (15) to 6000 (16). Studies reported response rates from 65 to 85%. Four studies did not report this measure, three of which were research reports not published in peer reviewed journals. Table 1 provides a synopsis with further details of all studies included in our review.

Beliefs about causes and definition of mental disorder
Six studies used case vignettes to elicit causal beliefs for depression and schizophrenia (1, 10, 12, 13, 15, 17-19) and were entered in our meta-regression analysis. Causal beliefs were assessed by offering respondents a list of causes for the problem described in the vignette and asking them to rate the likelihood of each cause. Because data from Scotland were reported separately for male and female characters depicted in the vignette, they are treated as two studies in our analyses. Figure 1 summarizes results of the analysis for two causal beliefs (“inherited/genetic” and “brain disease”). Together, the studies covered 16 years (1990-2006, x-axis). Agreement with “inherited/genetic” increased by 1.3% per year in schizophrenia (p<0.001), and by 1.2% in depression (p=0.007). The estimated increase over the entire time period across all studies was thus 20.8% (schizophrenia) and 19.2% (depression). This increase in biological causal beliefs was not accompanied by decreasing support for a psychosocial aetiology of schizophrenia and depression: Endorsement of stress as a cause remained unchanged at a high level (Table 2).

The meta-regression analysis also yielded coefficients for each country. They signify the differences of the estimates for each country in relation to the reference category, i.e. the amount the regression line needed to be moved up or down on the y-axis to depict estimates for the respective country. Since predictions for individual countries are not the focus of this paper, we omit these additional coefficients in our table. Country coefficients as well as all individual data extracted for our meta-analyses are available from the authors on request.

Two of the vignette-based trend analyses, from East Germany (12) and Australia (20), additionally examined whether respondents were able to correctly identify the unlabelled case-vignette as “depression” or “schizophrenia”, respectively. Both studies used open-ended questions to elicit the respondents’ problem definition. They show increasing illness-recognition in both countries: From 1993 to 2001 (East Germany) and 1995 to 2003/2004 (Australia), correct recognition of schizophrenia increased from 17% to 22%, and from 27% to 43%, respectively. Recognition of depression increased in East Germany to 38% (+11%), and in Australia to 67% (+27%).

Similar trends towards increased mental health literacy were found in studies with different methodology. In Great Britain (in the context of the Defeat Depression Campaign) the proportion of respondents endorsing “biological changes in the brain” as cause for “depression” increased from 33% in 1991 to 43% in 1997, and for stress from 71% to 83% (21). Two further studies explored public conceptions of general mental illness. One study, covering the exceptionally long time from 1950-1996 (22) showed a broadening of conceptions of mental illness, respondents mentioning a greater proportion of non-psychotic disorders when asked about their definition of mental illness in 1996 than in 1950. The comparison of two surveys conducted in Great Britain in 1990 and 1997 revealed an increase of 14% in the proportion of respondents spontaneously mentioning a specific mental disorder when asked what types of mental illness they can think of (23).
Attitudes towards help-seeking and treatment preferences

Figure 2 shows results of the meta-regression analysis of two important beliefs about help-seeking for schizophrenia and depression, based on four studies (1, 12, 17, 24-27). Recommendation to visit a psychiatrist for the problem described in the case-vignette increased significantly for depression (change per year 1.3%, p=0.008), and, from a higher baseline, just below significance in schizophrenia (change per year 0.9%, p=0.06). Similarly, drug treatment became significantly more popular for both disorders (change per year 1.7%, p=0.017 in schizophrenia, 1.3%, p=0.03 in depression). Between 1990 and 2006, this amounts to an estimated increase of recommending drug treatment for schizophrenia of 27.2%. Particularly with regard to drug treatment, Figure 2 shows that the direction of attitude change is similar even in countries with very different rates of approval (position of the circle in relation to the y-axis). Table 2 shows that recommendation of a GP, a psychotherapist or psychotherapy did not change significantly.

Studies with differing methodological approaches yielded similar results: A trend analysis from the U.S. (1990-2003) explicitly focusing on attitudes towards professional mental health treatment also showed that the American public became more accepting in this respect: While in 1990-1992 36% reported that they would “definitely go” for professional help, this number was 41% in 2001-2003 (28). Respondents in the more recent survey were also more comfortable talking with a professional about personal problems. A second study demonstrated improving attitudes towards psychiatric medication 1998-2006. More participants in 2006 than in 1998 thought that medications help people to deal with day-to-day stresses (83% versus 78%), make things easier in relation with family and friends (76% versus 68%), and help people feel better about themselves (68% versus 60%) (29). Similarly, a trend analysis from Germany using surveys from 1990 and 2001 showed that anticipation of negative effects from psychotropic drugs declined significantly (30).

Stereotypes about persons with mental illness

Stereotypes play a crucial role in theoretical models of stigmatization, because they supposedly trigger negative emotional responses and discrimination. Table 2 shows results of a meta-regression of trends for two common mental illness stereotypes, being dangerous and being to blame for the problem (13, 17, 18, 24, 31). These analyses are based on three studies only (being dangerous in schizophrenia: four studies), and neither trend reached statistical significance, although there was a trend towards reduced blame in schizophrenia and depression (p=0.10 and p=0.11).

Inconsistent results were found in other studies: In two surveys using diagnostic labels and conducted in the context of the Changing Minds Campaign of the Royal College of Psychiatrists in Great Britain 1998 and 2003, the perception of dangerousness decreased for both schizophrenia and depression, and blame slightly decreased (from 8% to 6%) for schizophrenia (31). Conversely, two studies examining general mental illness showed an increase of perceived dangerousness. The first study (U.S., 1950-1996) showed that the perception of mentally ill people being violent or frightening had substantially increased (22). A study from New Zealand (1999-2002) also showed a growing notion that people with mental illness are more likely to be dangerous than other people (32).

Social acceptance of people with mental illness

The final outcome of most theoretical models on stigma is social rejection and discrimination of persons with mental illness. In population surveys, this outcome is usually measured as “desire for social distance”, using items assessing the willingness or reluctance of respondents to engage in specific forms of everyday contact. Most studies using social distance scales reported willingness to engage socially with mentally ill persons, thus generating information about social acceptance (as opposed to social rejection). We included those items in our meta-regression analysis that were used most consistently across six studies assessing
social distance towards a person depicted in a case-vignette of either schizophrenia or depression (12, 13, 15, 17, 24): Accepting someone as a co-worker, as a neighbour, as a friend, and as someone marrying into one's family. Figure 3 shows a significant decline in accepting persons with schizophrenia as a neighbour (p=0.002) and as a co-worker (p=0.03), while no significant changes occurred in depression. Over the 16-year period covered by our meta-regression analysis, the estimated decline for accepting someone with schizophrenia as a neighbour accumulated to 15.5%, and to 17.8% for acceptance as a colleague at work. Table 2 shows that acceptance of more intimate relationships (acceptance as a friend and as someone marrying into one's family) did not change significantly for both disorders. In schizophrenia, this could indicate a “bottom effect”, because acceptance of these relationships was low from the beginning (estimated baseline in West Germany in 1990: 28% and 13%, respectively).

-Figure 3 about here-

Other studies investigated how attitudes toward people with mental illness in general developed over time. They found all either no change or inconsistent trends or even a trend towards a deterioration of public attitudes. Neither study showed evidence of a substantial increase of the public’s acceptance of people with mental illness over the last decades.

In the Netherlands the public had become more acceptant of former psychiatric patients between 1976 and 1987, but in 1997 it had again grown more reluctant to receiving ex-patients into their private life. For instance, while 51% accepted a psychiatric ex-patient as teacher for little children in 1976, and the percentage had increased to 66% in 1987, it dropped again to 56% in 1997 (33). In England and Scotland, surveys were carried out 1994-1997 annually, in 2000 and in 2003, using an adapted version of the Community Attitudes Towards the Mentally Ill (CAMI) survey (34). Over the 9 years, responses to two out of 25 items improved and responses to two items deteriorated for both England and Scotland. Comparing the years 2000 and 2003, i.e. the data collected immediately before and immediately after the “see me” Scotland campaign, there was significant deterioration for 17/25 items in England and only for 4/25 items in Scotland. (16). In Poland four surveys have been conducted over a time period of 12 years (1996, 1999, 2005, 2008), showing no substantial changes in the respondents’ desire for social distance in personal relationships, but somewhat more tolerant attitudes concerning the access of ex-patients to social roles such as mayor, politician, teacher, or priest. Fewer people responded friendly towards the mentally ill in 2008 than in 1996 (35-38).

**Discussion**

Our systematic review and meta-analysis revealed a consistent evolution of public attitudes across different countries. Two distinct developments emerged: First, the public’s literacy about mental disorders clearly has increased. Second, at the same time, attitudes towards persons with mental illness have not changed for the better, and have even deteriorated towards persons with schizophrenia. Throughout, results of our meta-regression analysis of studies using a similar methodological approach based on unlabelled case-vignettes of schizophrenia and depression were corroborated by the findings from other studies using different methods. This apparent validity of our findings is limited, however, by two factors: First, we cannot rule out that studies not indexed in one of the major English language databases PubMed, PsychINFO and Web of Science escaped our attention. We tried to overcome the dominance of English scientific literature by additionally asking international experts on psychiatric attitude research for any studies they were aware of, and by careful citation tracking within the literature we found. In fact, results of three of the 16 studies identified in this review (from Austria, The Netherlands and Poland) were published in their native language. Still, this does not overcome the second limitation: all studies identified originated from industrialized, first-world countries, and hence no conclusions on the evolution of attitudes in other countries is permissible.
While in some instances, results from different countries were numerically quite similar (regarding, for example, the role of heredity/genetics for the aetiology of depression or schizophrenia), we found considerable national differences in other respects (approval of drug treatment, social acceptance of persons with depression or schizophrenia). It is not possible to determine to what extent methodological differences like asking about “prescription medication” in general in the U.S. (1, 17) or specifically for “antipsychotics” for schizophrenia and “antidepressants” for depression in Australia (20) contributed to differing results, and to what extent they represent true national particularities. National differences, however, are not the subject of this review, but changes over time, and compellingly, even from very different baselines, changes frequently occurred in similar direction.

The first development, the apparent increase in mental health literacy illustrates that a bio-medical model of mental disorders enjoys growing popularity, which is consistent with the enormous efforts and achievements within psychiatry in understanding the biological correlates of mental illness and conceptualizing mental illness as “brain disease”. Little change occurred in the public’s strong endorsement of psychosocial stress as a major cause of mental disorders. This could be interpreted as an indication of a balanced view including psychosocial and biogenetic causal explanations, equivalent for example to a vulnerability-stress model of mental disorders. However, a study from Germany asking respondents to indicate the most and second most important cause for either depression or schizophrenia found most respondents supporting either two biological or two psychosocial causes, suggesting that if people need to prioritize their causal beliefs, they prefer either biological or psychosocial explanations, but usually not a combination of both (39).

Our findings also suggest that conceptualizing mental disorder as a brain disease or a medical problem facilitates acceptance of a medical-professional solution for this problem. There has been a general increase in the belief that mental illness requires professional help. The growing popularity of psychotropic medications is thereby not accompanied by a decrease in the popularity of psychotherapy, which the public still favours over drug-treatment of mental disorders. This trend in attitudes is reflected in increased use of mental health services (40) and sales of psychotropic medication (41).

This apparent success-story of psychiatric research and educational work is, however, incomplete. The second development evident from this review does not fuel optimism: Attitudes towards persons with mental illness have not changed for the better. Although there were insignificant trends towards reduced blame in schizophrenia and depression, notions of dangerousness did not change. Most strikingly, social acceptance of mentally ill persons did not increase since 1990. Instead, acceptance of persons with schizophrenia as a co-worker or neighbour diminished, and acceptance as a friend or in-law remained at low levels. Obviously, a better biological understanding of mental illness has not translated into greater social acceptance of mentally ill persons. The persistence of negative attitudes is even more sobering given that attitudes towards other minorities in western industrialised societies have indeed improved: For example, attitudes towards homosexuals have become considerably mor tolerant in many countries (42-44).

How can this failure to improve social acceptance of mentally ill persons be explained? Recently, it has been argued that a biogenetic causal model of mental illness is unlikely to improve attitudes towards persons with mental illness for both theoretical and empirical reasons: While a biogenetic illness model is commonly hypothesized to reduce perceived responsibility and thereby rejection of mentally ill persons, there is so far no evidence supporting this claim (45). Instead, attention has been drawn to potentially negative effects of biogenetic causal explanations on the stigma of mental disorders, because they may enhance notions of “otherness”, reduce treatment optimism, and aggravate anticipations of unexpected and dangerous behaviour (46-50). This could be particularly true for schizophrenia, where we found a deterioration of attitudes in some respects. Since we found neither a worsening nor an improvement of social rejection in depression, a potential association between biogenetic illness models and social acceptance is probably less relevant for this disorder. A population study from Germany examining the relation between social distance and causal beliefs regarding schizophrenia and depression points towards this direction (51), showing stronger associations between biological causal beliefs and negative attitudes in schizophrenia than in depression. However, these illness specific effects needs further exploration. On an individual level, qualitative studies among patients with affective disorders and their relatives have even indicated that biogenetic causal explanations are associated with reduced perceptions of stigma (52), but so far, quantitative studies have not supported such findings (53).
Our results thus provoke far reaching conclusions. While the approach to depict mental disorder as an “illness like any other” and to emphasize its biological correlates seems useful to enhance the acceptance of professional medical treatment for mental disorders, it is not suitable to improve social tolerance towards those suffering from mental illness. Dissemination of biological knowledge is not a solution to discrimination and stigmatization of persons with mental illness. Instead, it seems necessary to re-evaluate the public image of mental disorders psychiatry creates, and to arrive at communicating a more balanced, truly biopsychosocial disease model of mental disorders. Along this line, concerns have been voiced whether the “illness like any other” approach is generally appropriate to depict mental disorders (54). It has been argued, for example, that the “chemical imbalance” explanation for depression does not adequately represent the multitude of biological and social determinants of its onset and course (55), or that the “mental disorders are brain disorders” narrative carries an unduly “eliminative reductionist perspective” (56).

This seems especially important to anti-stigma and awareness campaigns. During the time covered by our analyses, many local and national campaigns have worked at improving public attitudes towards persons with mental illness (57). Seven studies included in our review were conceptualized to evaluate national campaigns. Overall, no consistent differences were observed between the results of these studies and those not explicitly connected to any interventions. However, since the evaluation of anti-stigma and awareness programs was not the focus of our review, no definite conclusions on their effectiveness can be drawn. An appropriate review of such campaigns would have needed to include both local and short-term studies, which we excluded in order to elicit broader and sustained time trends of attitudes. It is also important to note that the last survey included in a trend-study dated from 2006. Since actions to fight the stigma of mental illness have continued and intensified since, new trend analyses tracking present and future attitude changes are necessary. They would provide further feed-back for the ongoing efforts to increase social acceptance of those suffering from mental disorders. It seems clear from our review, however, that education about biological correlates of mental disorders is not sufficient to improve attitudes towards persons with mental illness. Effective anti-stigma programs need to embrace other strategies, centred for example on consumer contact (58). Recent large-scale anti-stigma-activities follow this rationale (59, 60), giving hope to finally arrive at improving attitudes and not merely increasing knowledge about mental illness.

Declaration of interest
H. J. Grabe: Speakers honoraria from Bristol-Myers Squibb, Eli Lilly, Novartis, Eisai, Wyeth, Pfizer, Boehringer Ingelheim, Servier and travel funds from Janssen-Cilag, Eli Lilly, Novartis, AstraZeneca and SALUS-Institute for Trend-Research and Therapy Evaluation in Mental Health. M. C. Angermeyer: Lecturer fees from AstraZeneca, Janssen-Cilag, Eli Lilly, and Pfizer. Research grants from GlaxoSmithKline and Lundbeck. All other authors declare no conflicts of interest.

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### Table 1. Synopsis of national trend analyses of public knowledge about mental disorders, attitudes towards help-seeking and treatment, and attitudes towards mentally ill people

<table>
<thead>
<tr>
<th>Country</th>
<th>Time period</th>
<th>Sample size</th>
<th>Response rate (%)</th>
<th>Age range (years)</th>
<th>Stimulus</th>
<th>Mental illness unspecified</th>
<th>Schizophrenia</th>
<th>Depression</th>
<th>Other disorder</th>
<th>Knowledge</th>
<th>Attitudes towards help-seeking/treatment</th>
<th>Attitudes towards the mentally ill</th>
<th>Anti-stigma/awareness campaign</th>
<th>Litera-ture</th>
</tr>
</thead>
<tbody>
<tr>
<td>Great Britain</td>
<td>1990-1997</td>
<td>?/1804</td>
<td>-a</td>
<td>15+</td>
<td>L</td>
<td>√</td>
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<tr>
<td>U.S.</td>
<td>1990-2003</td>
<td>5388/4319</td>
<td>82/71</td>
<td>18-54</td>
<td>L</td>
<td>√</td>
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<tr>
<td>Great Britain</td>
<td>1998-2003</td>
<td>1737/1725</td>
<td>67/65</td>
<td>16+</td>
<td>L</td>
<td>√</td>
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<tr>
<td>U.S.</td>
<td>1998-2006</td>
<td>1387/1437</td>
<td>76/71</td>
<td>18+</td>
<td>L</td>
<td>√</td>
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<tr>
<td>New Zealand</td>
<td>1999-2002</td>
<td>1017</td>
<td>65/7</td>
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<td>L</td>
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<tr>
<td>Germany (West)</td>
<td>1990-2001</td>
<td>6165/4005</td>
<td>66/65</td>
<td>18+</td>
<td>V</td>
<td>√</td>
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<tr>
<td>Germany (East)</td>
<td>1993-2001</td>
<td>1564/1020</td>
<td>71/65</td>
<td>18+</td>
<td>V</td>
<td>√</td>
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<tr>
<td>Country</td>
<td>Period</td>
<td>Sample Size</td>
<td>Age Group</td>
<td>Years</td>
<td>Case</td>
<td>Vignette</td>
<td>Meta-Regression</td>
<td>Notes</td>
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<tr>
<td>Austria</td>
<td>1999-2007</td>
<td>1042/988</td>
<td>16+</td>
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<tr>
<td>U.S.</td>
<td>1996-2006</td>
<td>1444/1523</td>
<td>18+</td>
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<tr>
<td>Scotland</td>
<td>2002-2004-2006</td>
<td>1381/1401/1216</td>
<td>16+</td>
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</tbody>
</table>

*quota sampling  b alcoholism, eating disorder, dementia  c alcoholism  d only in Scotland  e only in some states  L Diagnostic label  V

Case-vignette (included in meta-regression analysis)
Table 2: Meta-regression analyses of time-trends of causal beliefs, treatment recommendations, negative stereotypes and social acceptance 1990-2006, based on studies using case-vignettes of schizophrenia or depression.

<table>
<thead>
<tr>
<th>Causal beliefs (n=6)</th>
<th>Schizophrenia</th>
<th>Depression</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Change per year adjusted for country (^a)</td>
<td>Intercept (estimation for Germany West in 1990) (^b)</td>
</tr>
<tr>
<td></td>
<td>[%] 95% CI</td>
<td>P value</td>
</tr>
<tr>
<td>Inherited or genetic</td>
<td>1.32 0.82 – 1.82</td>
<td>&lt;0.001 43.8 38.3 – 49.3</td>
</tr>
<tr>
<td>Brain disease (^c)</td>
<td>1.22 0.11 – 2.35</td>
<td>0.037 53.9 42.1 – 65.7</td>
</tr>
<tr>
<td>Stress</td>
<td>0.06 -0.20 – 0.33</td>
<td>0.61 71.9 68.8 – 75.1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Treatment recommendations (n=4)</th>
<th>Schizophrenia</th>
<th>Depression</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychiatrist</td>
<td>0.92 0.09-1.93</td>
<td>0.06 69.2 57.9-80.5</td>
</tr>
<tr>
<td>Psychotherapist (^d)</td>
<td>1.17 -0.33-2.66</td>
<td>0.097 64.8 51.9-77.8</td>
</tr>
<tr>
<td>GP</td>
<td>0.14 -1.53-1.82</td>
<td>0.80 65.0 46.8-83.3</td>
</tr>
<tr>
<td>Drug treatment</td>
<td>1.68 0.57-2.78</td>
<td>0.02 35.0 23.0-47.1</td>
</tr>
<tr>
<td>Psychotherapy (^d)</td>
<td>0.59 -0.02-0.04</td>
<td>0.61 66.0 40.3-91.7</td>
</tr>
</tbody>
</table>
### Stereotypes (n=3)

<table>
<thead>
<tr>
<th>Stereotype</th>
<th>Estimate</th>
<th>95% CI</th>
<th>Standard Error</th>
<th>Lower CI</th>
<th>Upper CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dangerous</td>
<td>0.43</td>
<td>-0.90 to 1.75</td>
<td>0.44</td>
<td>0.34</td>
<td>2.95</td>
</tr>
<tr>
<td>To be blamed</td>
<td>-1.12</td>
<td>-2.56 to 0.32</td>
<td>0.10</td>
<td>0.11</td>
<td>0.52</td>
</tr>
</tbody>
</table>

### Social acceptance (n=6)

<table>
<thead>
<tr>
<th>Social Acceptance</th>
<th>Estimate</th>
<th>95% CI</th>
<th>Standard Error</th>
<th>Lower CI</th>
<th>Upper CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Co-worker h</td>
<td>-1.11</td>
<td>-2.08 to -0.13</td>
<td>0.033</td>
<td>0.07</td>
<td>1.90</td>
</tr>
<tr>
<td>Neighbour</td>
<td>-0.97</td>
<td>-1.47 to -0.47</td>
<td>0.002</td>
<td>-0.06</td>
<td>-1.11</td>
</tr>
<tr>
<td>Friend h</td>
<td>-0.89</td>
<td>-2.08 to 0.30</td>
<td>0.12</td>
<td>0.51</td>
<td>-2.02</td>
</tr>
<tr>
<td>Marrying to family</td>
<td>-0.03</td>
<td>-0.48 to 0.42</td>
<td>0.87</td>
<td>0.45</td>
<td>-0.69</td>
</tr>
</tbody>
</table>

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*a Estimated change of agreement to a specific cause, treatment recommendation, stereotype, or willingness to engage in a specific form of social contact (per year, %) across all studies included.

*b Estimated baseline for any change in 1990 for the reference category, West-Germany (%).

*c n=5

*d n=3, not adjusted for country because of the small number of observations

*e n=4

*f not adjusted for country because of the small number of observations

*g Estimation for United States in 1996 (no published data for West-Germany)

*h n=5
Figure legends

Figure 1:

Evolution of causal explanations for schizophrenia and depression. Results from representative, national trend studies using unlabelled case vignettes.

Agreement to a specific cause, meta-regression analysis controlled for study site, reference category: West Germany. The position of each circle represents the result (y-axis) and year (x-axis) of one national survey, circle size is proportional to sample size. Surveys from different countries/trend-analyses are distinguished by different shades of grey.

Germany W: West Germany (old FRG)
Germany E: East Germany (former GDR)
(F): Female vignette
(M): Male vignette
**Figure 2:**

Evolution of treatment recommendations for schizophrenia and depression. Results from representative, national trend studies using unlabelled case vignettes.

Recommendation of a specific treatment, meta-regression analysis controlled for study site, reference category: West Germany. The position of each circle represents the result (y-axis) and year (x-axis) of one national survey, circle size is proportional to sample size. Surveys from different countries/trend-analyses are distinguished by different shades of grey.

Germany W: West Germany (old FRG)

Germany E: East Germany (former GDR)
Figure 3:

Evolution of social acceptance of persons with schizophrenia or depression. Results from representative, national trend studies using unlabelled case vignettes.

Willingness to engage in specific forms of social contact, meta-regression analysis controlled for study site, reference category: West Germany. The position of each circle represents the result (y-axis) and year (x-axis) of one national survey, circle size is proportional to sample size. Surveys from different countries/trend-analyses are distinguished by different shades of grey.

Germany W: West Germany (old FRG)

Germany E: East Germany (former GDR)

(F): Female vignette

(M): Male vignette