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German Alliance for Mental Health: anti-stigma project

Conception and implementation of interventions to destigmatize mental illness: recommendations and results of research and praxis

1.   Introduction

One out of four Germans suffers a mental illness during his life. However, mental illness is a taboo in our society and connected with discrimination and stigmatization at school, at work, in the family and within friendships. For the last approximately five years several organizations and institutions have been implementing anti-stigma interventions in Germany. However, these interventions focus on a few target groups only, most of them are not implemented throughout the nation and many have not been evaluated. The anti-stigma project of the German Alliance for Mental Health, which is funded by the Federal Ministry of Health, aims at facing these deficits. The purpose of this project is to conceptualize and implement an intervention based on scientific facts, focusing on relevant target groups and including an evaluation to achieve sustainable effects in reducing stigma and discrimination because of mental illness. Prior to the conception of the intervention itself a scientific analysis was performed. This analysis contains current theories and research results regarding stigma and anti-stigma work, an international literature review of anti-stigma interventions, a survey of unpublished German anti-stigma interventions, and an investigation of the needs of people with mental illness and their families. The anti-stigma intervention will be based on the results of the analysis, which are summarized in the following. For the full report see the paper "Konzeption und Umsetzung von Interventionen zur Entstigmatisierung seelischer Erkrankungen: Empfehlungen und Ergebnisse aus Forschung und Praxis".

2.   Anti-stigma-Research: results of international publications

In order to determine the current state of research concerning anti-stigma approaches, theories on the origin of stigma and prejudices were analyzed, as well as reviews about interventions to reduce stigmatization of people with mental illness and some minority groups (e.g. homosexuals, blacks etc.). Furthermore, intervention studies were analyzed, which aim to detect effective strategies to destigmatize mental illness. For the conception of future interventions the following recommendations could be derived.

Typically, stigma is deeply rooted within a society and has multiple causes in the personality of the stigmatizers (e.g., their lack of knowledge or fear of the stigmatized person), interpersonal experiences (e.g., a lack of contact or the perception of unjustified privilege for some stigmatized groups), and existing societal structures and stereotypes which are often maintained if not fostered by the media and the judicial system. Accordingly, interventions to reduce stigma can be differentiated regarding the level on which the interventions operate (Paluck & Green, 2009; Heijnders & van der Meij, 2006; Wagner, Christ & van Dick, 2002; Wagner & Farhan, 2008). Following the categorization of Wagner et al., we differentiate between measures that aim at the *societal* level, the *interpersonal* level or the *individual* level.

Prof. Dr. Wolfgang Gaebel, Dipl.-Pol. Wiebke Ahrens, Dipl.-Psych. Pia Schlamann

German Alliance for Mental Health: anti-stigma project

Programs on the societal level aim at changing the presentation of minority groups in the media or with nationwide information campaigns. Similarly, public campaigns that involve influential people as role-models can be used to change the image of a stigmatized group and to establish a new norm about the non-acceptability of stigmatizing attitudes against this group. For the purpose of the empowerment approach the conception and implementation of such campaigns should involve people with mental illness. Other strategies on the societal level include legislative changes, i.e. amendments and changes of norms, or protest against stigma and discriminatory perceptions of people with mental illness. However, protest runs the risk of inducing reluctance and resistance against attitude change.

Programs operating on the interpersonal level aim at changing individuals' perception of the stigmatized group, either by emphasizing a common identity ("We are all humans/mothers/Europeans/Americans….") or by providing an opportunity for interpersonal contact to people with mental illness to the effect that stereotypes can be reappraised (Pettigrew & Tropp, 2006). Of these, the latter is the most effective method to reduce the stigma of mental illness leading to strong and persistent attitude changes (Schachter et al., 2008). Personal contact with people with mental illness should be interactive to be effective.

Finally, interventions can target the individual level, e.g. by changing an individual's attitudes or personality traits. For instance, lack of self-confidence is associated with stigma, and enhancing an individual's sense of the self can lead to reduced prejudice (Rubin & Hewstone, 1998). Other individual-level approaches target moral development (e.g. by pointing out the inconsistency between one's own values of personal freedom and prejudiced attitudes), enhance empathy and perspective-taking (e.g. by means of entertainment media such as books or movies) or improve knowledge about the stigmatized group. The most effective intervention on the individual level is education addressing existing misconceptions about mental illness and improving knowledge, e.g. about mental illness causes. As biogenetical explanations can increase fear and the desire of social distance, the focus should be on multicausal theories. Education in the form of teaching units appears to be particularly effective, primarily when using several elements, such as videos, and computer-based or active elements besides lectures. Furthermore, interventions that aim at enhancing empathy and perspective taking, e.g. by means of role-play, films or books, have proven effective in reducing stigma.

Based on Paluck & Green's (2009) review of 985 studies, the most successful interventions include the following elements: the provision of information about the stigmatized group, the opportunity for personal contact or other elements that facilitate perspective-taking, and the promotion of new social norms that are irreconcilable with prejudiced attitudes. The latter can be achieved for instance through a role-model for non-stigmatizing behavior, legislative changes or non-stigmatizing depiction in the media. Reviews focusing on illness-related stigma such as HIV/Aids, leprosy, TB, mental illness and epilepsy (Heijnders & van der Meij, 2006; Brown, Macintyre & Trujillo, 2003) point out the importance for anti-stigma interventions to be multi-targeted and oriented at several of the mentioned levels, because "no 'magic bullet' is available to alter something as complex as the stigma of a disease" (Brown et al., 2003, p.66).

Prof. Dr. Wolfgang Gaebel, Dipl.-Pol. Wiebke Ahrens, Dipl.-Psych. Pia Schlamann

German Alliance for Mental Health: anti-stigma project

Concerning target groups, pupils and students are promising groups. They are easy to address and often more flexible in attitudes and behavior. Health professionals seem to be a further group that is easy to destigmatize. The analysis showed that future interventions should also be aimed at other target groups, such as persons with mental illness themselves, the media and government agencies.

3. Interventions to reduce mental illness stigma worldwide: results of international literature

A literature review was conducted in order to summarize and analyze current and past global efforts, approaches and activities directed at removing stigmatization of mental illness and those related to it. A systematic search process in electronic databases (Medline, PubMed, PsycInfo, Embase) was performed in order to obtain all relevant publications. Of the 14.000 records entered into initial relevance screening, 82 publications on 63 anti-stigma projects and campaigns were identified and analyzed. In the following, the preliminary results of the review are summarized.

Since the year 2003, a world-wide increase in efforts to reduce stigmatization can be observed. The World Psychiatric Association (WPA) International Programme to Fight the Stigma and Discrimination because of Schizophrenia "Open the Doors" led to a further increase in anti-stigma efforts in 2006 before activities decreased slightly in the following years. Most of the activities aimed at reducing stigmatization took place in the English-speaking world, with the USA leading, followed by Great Britain ranking second and Australia ranking third. Moreover, the majority of the activities are local projects and projects on regional or national level can hardly be found in Germany. Almost all of the national campaigns originated in English-speaking countries. Furthermore, most of the international programs are not disease-specific, that is, interventions are not aimed at the destigmatization of a specific disease or disorder, but rather mental illness in general. The main disease-specific projects fight the stigma and discrimination of schizophrenia as they are frequently connected with the "Open the Doors" program.

The main strategy used in nearly all reviewed interventions is education. The goal of educational programs is the destigmatization via transfer of knowledge about mental illnesses and education on prejudices existing in the community. Educational programs make use of teaching units and courses in schools and universities, the media, cultural events, and public panel discussions, for example. Frequently, a combination of intervention methods is used. For example, educational programs are combined with contact to people with mental illnesses. In accordance with the results of anti-stigma research, interventions involving contact belong to the most effective. About 60 % of the reviewed projects use this approach. Furthermore, national campaigns use the media, advertisements, the press and websites on the internet in order to achieve education with as broad an impact as possible in the general public and with relatively little effort.

Concerning the target groups, the international comparison shows that pupils and students constituted the main target group in evaluation research. One reason for the greater amount of interventions aimed at young people is the finding that activities to change attitudes should begin at an early stage in life before attitudes and stereotypes have grown too firm. Furthermore, searching for one's own identity during puberty and

Prof. Dr. Wolfgang Gaebel, Dipl.-Pol. Wiebke Ahrens, Dipl.-Psych. Pia Schlamann

German Alliance for Mental Health: anti-stigma project

the accumulation of emotional crises in adolescence can be seen as further factors facilitating the effects of anti-stigma efforts within this target group. The important and moreover easily accessible target group of pupils is overrepresented in Germany according to the international comparison. Students, the general public, an internationally frequently used target group, family members of persons with mental illnesses, and health professionals are underrepresented as target groups in Germany. For that reason, future projects in Germany should primarily focus on the general public and health professionals.

Overall, the methods of evaluation used internationally for the various anti-stigma projects do not allow for meaningful conclusions. The study design generally used is a quantitative pre-post design, with less than 30% of the reviewed studies using a control group, thus not allowing a clear attribution of the measured changes to the effects of the intervention. For the most part, statements concerning the long-term effects of interventions cannot be made on account of the low number of follow-up studies conducted. The measures used in the reviewed studies have to a large extent not been validated. As the validity of an instrument indicates whether the data represent the intended variable, only validated instruments allow for a meaningful interpretation of data. A further limitation of the studies included in the present review lies in the choice of target criteria. For instance, according to the current state of research, social distance is the most important criterion in measuring stigmatizing behavior. Social distance is measured by asking participants to judge whether they would accept a person with mental illness or to what extent they would feel uncomfortable in the presence of a person with mental illness, if that person were a neighbor, an acquaintance, a friend or partner. Despite being one of the most important measures of stigmatizing attitudes, social distance was only measured in 60% and affected positively through interventions in only 20% of the reviewed studies.

Conclusions concerning the effects and the sustainability of the interventions are often not reliable due to the mentioned methodological limitations of most studies. Future projects should therefore be evaluated ideally using validated measures of stigmatizing behavior, such as social distance, a control group and a follow-up study after an adequate time interval.

4. Interventions to reduce mental illness stigma in Germany: results of a national survey

In order to summarize unpublished past and current anti-stigma activities in Germany, a questionnaire was developed, which was broadcasted via Email. Altogether 126 questionnaires were sent back from 95 project executing organizations, some questionnaires including several projects. Overall, 55 information and training projects, 52 movie and culture projects, 30 school projects, 23 projects providing interpersonal contact and trialogical communication, 11 press and public projects and 10 action/open days were reported.

Although many target groups were not well-defined, most interventions focused on the public, pupils and teachers, health professionals or people with mental illness and their families. Many interventions focus on several of the mentioned target groups. As was the

Prof. Dr. Wolfgang Gaebel, Dipl.-Pol. Wiebke Ahrens, Dipl.-Psych. Pia Schlamann

German Alliance for Mental Health: anti-stigma project

case for the target groups, the intervention's aims were not well-defined and differing and in some cases several aims were mentioned. Education was mentioned 69 times, destigmatization 45 times, contact and empowerment 43 times and prevention and care 27 times. There were no quantitative, measurable aims, thus complicating evaluation.

Concerning project executing organizations psychiatric and psychotherapeutic institutions play a central role, performing more than one-third of all projects. Even social psychiatric or psychiatric community care institutions and public institutions such as public health departments, the psychiatry coordinator or the administration of cities/regions frequently perform projects or act as cooperation partners. There are hardly any institutions not connected with psychiatric care or self-help, performing anti-stigma interventions.

The main anti-stigma activities involve people with mental illnesses and/or their relatives. Frequently, cooperation with self-help associations takes place in the field of anti-stigma work. Most projects are local and few projects are regional or national. The majority of the interventions have been performed multiple times or continuously for years which is beneficial regarding the sustainability of the change in attitudes.

5. Demands regarding contents and target groups for anti-stigma-interventions: results of research and interviews with members of self-help organizations and people with mental illness

In order to detect areas of stigmatization and discrimination and priorities regarding settings, target groups etc. for future anti-stigma activities, the following, mostly qualitative analysis was done:

- Examination of international scientific (in parts representative) studies
- Interviews with representatives of German self-help organizations
- Two focus groups with a total of 20 persons with mental illness, who are not organized in self-help organizations

The scientific studies analyzing the experiences of people with mental illness lead to the conclusion that these people experience stigmatization and discrimination particularly in interpersonal relations. Concerning the workplace, people with mental illness not only experience but mainly anticipate stigmatization. The public image of people with mental illness, which is formed basically by media depiction, is stigmatizing, too.

Apart from the above mentioned areas workplace, families, and friendships, the focus groups described psychiatric and medical care and government agencies as areas where negative experiences because of mental illness are made. However, many participants also report support from their partner, friends or family.

The representatives of the self-help organizations mentioned the following areas as to date not sufficiently considered or as relevant for future anti-stigma activities:

- Psychiatric care, among others psychiatric hospitals
- workplace
- society in general, particularly communities
- health care system and social framework (health insurances, social welfare office and federal employment office)

Prof. Dr. Wolfgang Gaebel, Dipl.-Pol. Wiebke Ahrens, Dipl.-Psych. Pia Schlamann

German Alliance for Mental Health: anti-stigma project

- police and judiciary (e.g. family court)

The interviewees mainly mentioned areas in which they see some possibilities to counter exclusion and discrimination of people with mental illness. In addition, one interviewee focused on general public education.

The following proposals for the conception of future anti-stigma interventions could be derived from the interviews:

- Health professionals and staff of health insurances, government agencies etc. are important target groups and at the same time important multiplicators

- The necessity to connect anti-stigma activities to psychiatric care structures or to advance these structures via anti-stigma activities

- Interaction between destigmatization and integration of the persons concerned in community/public life constitutes a central aspect

- Future anti-stigma activities targeting a specific group (profession) should be conducted in cooperation with the according professional association

- positive appraisal of the current anti-stigma school projects

Participants of both focus groups discussed the necessity of changes in contact with people with mental illness in health care. In their opinion, greater importance should be placed on educating the persons concerned and to strengthen them as "experts for their own interests". As relevant areas for future anti-stigma interventions focus group participants mentioned the areas in which they had made stigmatization experiences: psychiatric care, workplace, government agencies (mainly federal employment offices), and families. In their opinion, important target groups are employers, physicians, therapists, and the staff of government agencies.

6.   Conclusions

Anti-stigma research shows that interventions to destigmatize mental illness should work on different levels at the same time in order to achieve societal and structural changes and to reach the society and specific groups of persons through education and interpersonal contact. The application of education and structural changes are of utmost importance to achieve sustainability. A combination of different (educational) methods should be included in the intervention. It is important to address children and adolescents in anti-stigma work, as has been the case in many German projects so far. According to the results of the analysis of the demands the following areas are important for future interventions: the general public including the environment of the persons concerned in the communities as well as the workplace including federal employment offices, psychiatric care, medical care and interpersonal relations (families, friends). As these areas are connected with different target groups and different aspects of stigmatization, several interventions are necessary to address all groups of persons. Ideally, these interventions are connected through a common structure in order to strengthen one another. A project with a smaller range should focus on an area detected as very relevant in the analysis of the demands: public/media, workplace or psychiatric care. The anti-stigma project of the German Alliance for Mental Health will target the workplace

Prof. Dr. Wolfgang Gaebel, Dipl.-Pol. Wiebke Ahrens, Dipl.-Psych. Pia Schlamann

German Alliance for Mental Health: anti-stigma project

because there is a lack of interventions targeting this area in Germany compared to the public/media and psychiatric care. A further reason is the current relevance of the topic "mental health at the workplace", e.g. one of the central themes in the European Pact for Mental Health and Well-Being from June 2008 is "Mental Health in Workplace Settings".

The use of a high-quality evaluation methodology is important in order to be able to draw well-grounded conclusions from the results concerning the effectiveness and sustainability of the implemented interventions and to improve them if necessary.