

Chapter 7

Mental Health and Stigma—Aspects of Anti-Stigma Interventions

Lars Hansson

7.1 Introduction

Negative public attitudes towards persons with mental illness have been identified as an important obstacle for recovery from illness and from becoming full participants in the society (Thornicroft 2006). The concept of stigmatization has been described and operationalized by many researchers (Link et al. 2001). The term was originally used to refer to a brand or scar burned or cut into the body, used to identify slaves and criminals.

In modern times stigma has often been used to denote some form of community sanction that marks an individual as being unacceptably different from the general population with whom she or he interacts (Goffman 1963). Stigmatization should therefore be seen as a social psychological phenomenon that originates in the relationships between individuals and between groups and constitutes a threat to the targeted individual's self-esteem and identity (Link et al. 1989). Even if a clear consensus about the conception of stigma is lacking, it is usually used in mental health research as a complex of problems that emanates from a lack of knowledge about mental health problems, negative attitudes and excluding or avoiding behaviour towards individuals with mental illness. Link and Phelan (2001) made an important contribution in response to the criticism that the stigma concept had been too vaguely defined and individually focused. They further developed the existing “labelling theory” of stigma and defined the stigmatization process as the co-occurrence of several components. A first component is the distinction and labelling of human differences. A second phase is that cultural beliefs link labels and persons to certain undesirable characteristics or negative stereotypes, in the case of mental illness such characteristics may be violence and dangerousness. Labelled

L. Hansson (✉)

Mental Health Services Research, Department of Health Sciences, Lund University,
PO Box 157, 221 00 Lund, Sweden
e-mail: lars.hansson@med.lu.se

persons are in a third step placed in distinct categories in order to establish a separation of “us” from “them” which may lead to that labelled persons experience status loss, discrimination and social exclusion. An important feature of Link and Phelan’s model is that stigmatization is linked to access to social, economic and political power which is necessary for these processes of disapproval, rejection, exclusion and discrimination to occur.

7.2 Current Status

7.2.1 *Public Stigma and Discrimination*

Stigma and discrimination are still prominent features of the life situation of persons with mental illness, adding to the burden of living with a mental illness. The vision that the deinstitutionalization of mental health services and the development of community-based services would lead to an integration of people with mental illness and thereby diminish stigma and discrimination have not come true (Angermeyer et al. 2006). Stigma and discrimination in many ways affect people with a mental illness causing a lowered self-esteem and quality of life, affecting possibilities of adequate housing, work and financial situation in a negative way (Sharac et al. 2010; Link et al. 1989; Yanos et al. 2001). Common misconceptions are that people with mental illness are violent, dangerous and unpredictable. Independent factor analyses of responses to population surveys have revealed three recurring attitude themes: (a) fear and exclusion, indicating a wish for social distance from people with mental illness; (b) authoritarianism, people with mental illness are irresponsible and cannot take care of themselves; (c) benevolence, people with mental illness are childlike and need to be cared for (Brockington et al. 1993). The relationship between gender and stigmatizing attitudes is inconsistent, and this goes for educational level and urban/rural setting as well (Schomerus et al. 2012). The only consistent finding is that familiarity with mental illness, in terms of having kins or friends with a mental illness, is related to more positive attitudes.

Stigma is also a major barrier to help-seeking causing not seeking treatment, delays, dropout and non-adherence to treatment (Gulliver et al. 2010). This is particularly problematic in the light of the development of a number of evidence-based interventions for people with mental illness, including supported employment, family interventions, illness management and integrated services for the most severely ill (Kuipers et al. 2014). Barriers may exist on a person-level, provider- and system-level. Person-level barriers include stigma related attitudes and behaviour leading to avoiding treatment. Provider level barriers may include access and availability of effective services and attitudes and beliefs of health service staff (Corrigan et al. 2014). Reviews of studies focusing attitudes of mental

health staff have shown that attitudes of a wish for social distance and treatment outcome pessimism are common among staff, and in some studies more common than in the general public (Schulze 2007).

Although stigma has been an issue since early research in the 1960s (3), there is no evidence of major changes in stigma and discrimination. Negative attitudes, stereotypes and discrimination are still highly prevalent and at least in the Western world remarkably stable between various national surveys (Angermeyer et al. 2006; Crisp et al. 2000; Heather et al. 2001). There seem to be some evidence that, although a great variation between countries exists, stigma of mental illness seem to be less severe in non-Western cultures (Fabrega 1991). For western countries the main conclusion is that public attitudes have not changed during the last two decades, or even turned worse in the case of people with schizophrenia (Schomerus et al. 2012). Although stigma is based on the expression of generalizations and stereotypes, there seem to be a gradient in for example the wish for social distance between different mental health conditions. Stigmatizing responses seem to appear along a gradient from “troubled person” to depression to schizophrenia to alcohol dependence, and finally, to drug dependence, which is exposed to the most severe negative attitudes of social distance (Pescosolido 2013).

The generally expanding scientific literature on mental illness stigma has so far no correspondence in studies on discrimination, where there still is a lack of studies. Discrimination deals with people’s behaviour as captured by observational studies, by studies of structural discrimination, for example related to the judicial system, or by studies focusing on the experiences of people with mental illness. The International Study of Discrimination and Stigma Outcomes study (INDIGO) performed a quantitative cross-sectional study of people with schizophrenia covering 27 countries which showed that perceived discrimination was common in a number of areas and most prevalent in areas of making or keeping friends, family members, and in finding and keeping a job (Thornicroft et al. 2009). A majority of the participants also reported anticipated discrimination in applying for work/education and making close relationships. Almost 75% of the participants concealed their diagnosis to their social network. A study made in cooperation with the Global Alliance of Mental Illness Advocacy Networks including people with schizophrenia and bipolar disorder focused more on perceived anticipated stigma and self-stigma (Brohan et al. 2010, 2011). They reported, for both conditions, that a majority had moderate or high perceived discrimination, that almost half of people with schizophrenia reported moderate or high levels of self-stigma, and that the equivalent figure for people with bipolar disorders was around one fifth of the participants. Referring to stigma as a barrier to treatment there is also evidence from some discrimination studies that people with mental illness feel patronized, humiliated and punished in contact with services and that patients point out mental health staff as one of the groups which are the most stigmatizing (Thornicroft et al. 2007; Hansson et al. 2014). The scarcity of studies investigating perceived discrimination makes further studies of perceived discrimination an urgent task in order to gain knowledge of the user perspective of discrimination.

7.2.2 Anti-stigma Interventions Challenging Public Stigma

The rising concerns about the multi-faceted negative consequences of mental illness stigma have led to an increase in the scientific interest of the stigma issue. This holds both for descriptive cross-sectional population surveys, qualitative studies with people with own experience as informants and for intervention studies focusing outcome and process of the rising number of national, regional or local anti-stigma programmes launched during the last decades. A summary of the research performed reveals that approaches to change public stigma seem to follow three strategies or combinations of these: protest, education and contact (Corrigan et al. 2012). Protest actions highlight misconceptions of mental illness for example in media or the injustice in various stigmatizing descriptions and presentations. Education is focusing an exchange of myths about mental illness with facts in order to improve mental health literacy. The assumption is that replacing myths with facts will improve attitudes and intended behaviour towards people with mental illness. Social marketing campaigns, including books, videos and webpages are examples of this, as well as more targeted educational strategies to specific target groups such as the police or health care staff. Contact strategies includes interpersonal contact with persons with own experience of mental illness. These contacts may be divided into personal face to face contacts and contacts via video or other audiovisual media. The hypothesis is that personal contact will disconfirm stereotypes and lessen levels of negative attitudes. Outcome measures in this research may mainly be divided into three categories, changes in attitudes, mental health literacy and behaviour, in most studies measured as intended behaviour.

A recent meta-analysis of 72 outcome studies focusing public anti-stigma interventions showed that both education and contact strategies had positive effects on reducing stigma both for adults and adolescents (Corrigan et al. 2012). Comparisons between contact and educational interventions showed that contact was more effective than education in reducing stigma for adults, while the opposite was found for adolescents. The meta-analysis also showed that interventions including social and personal face to face contacts with people with lived experience were more effective than video contacts. Only few studies included protest actions which showed not to be effective. The lack of evidence for effectiveness of protest actions is probably the main explanation why this research field has not expanded. This review mainly included short-term outcomes of interventions which is a drawback. To be more inclusive and informative for future action longer term outcome would be more interesting. A recent systematic review focusing medium- and long-term outcome of intervention studies to reduce stigma show less optimistic results (Thorncroft et al. 2016). This review showed only modest evidence for the effectiveness of anti-stigma interventions beyond 4 weeks follow-up, in terms of increased knowledge or reduced stigmatizing attitudes. In contrast with the

meta-analysis by Corrigan et al. (2012) social contact strategies did not show to be more effective in the medium to long term for improving attitudes. The authors conclude that methodological strong research is highly needed as a basis for investment in further anti-stigma interventions.

During the last decades a number of national and international campaigns and anti-stigma programmes have been launched. Rather few of these have been the subject of systematic evaluations in order to investigate outcomes of these programmes. An attempt to evaluate Beyondblue: the national depression initiative in Australia showed that high exposure regions had greater positive changes in beliefs about treatment and benefits of help seeking in general (Jorm et al. 2005). Recent evaluations of the Time to Change programme focusing whether public knowledge, attitudes, desire for social distance and reported contact in relation to people with mental health problems had improved in England during 2009–2015 showed that there were small but significant improvements during the period in all outcomes (Henderson et al. 2016). The campaign had more impact on the attitudes of the target age group, 25–45, than those aged over 65 or under 25. Women’s reported contact with people with mental health problems increased more than did men’s. Likewise, yearly population surveys in connection to a Swedish national anti-stigma programme running between 2010–2014 showed that a campaign primarily based on social contact theory and involving people with lived experience of mental illness may, even in a rather short-term perspective, have a significant positive impact on mental health literacy, attitudes and intentions of social contact with people with mental illness (Hansson et al. 2016).

7.2.3 Self-stigma and Anti Self-stigma Interventions

The internalization of negative stereotypes about mental illness occurs early in life throughout childhood and adolescence and may lead to the development of self-stigma for people afflicted by mental illness later on in life (Corrigan et al. 2006). Self-stigma (or internalized or felt stigma) exists on the individual level and indicates that the individual endorses stereotypes of mental illness, finds these stereotypes relevant and anticipates social rejection. Self-stigma is highly prevalent in people with longstanding and severe mental illness; a review of studies investigating prevalence of self-stigma showed prevalence rates in the range of 27–49% (Livingston et al. 2010). Self-stigma may also be a response to actual experiences of public stigma and discriminatory behaviour, which could result in consequences in a number of psychosocial life aspects: refraining from applying for work, avoiding contact with mental health care and social contacts. A recent review showed that public stigma and self-stigma was found to be the most important perceived barrier for people with mental health issues to actually seek help (Gulliver et al. 2010).

Despite the substantial evidence for the negative effects of self-stigma, the development of interventions to address it is a relatively new area of research. One recent review of self-stigma reduction interventions included 14 studies, of which

eight reported significant improvement in self-stigma outcomes (Mittal et al. 2012). Six self-stigma reduction strategies were identified; of which psychoeducation was the most frequently tested intervention. Two prominent approaches for self-stigma reduction emerged: interventions that attempt to alter the stigmatizing beliefs and attitudes of the individual; and interventions that enhance skills for coping with self-stigma through improvements in self-esteem, empowerment and help-seeking behaviour. A second recent narrative review, using slightly different inclusion criteria, also identified six approaches (Yanos et al. 2015). The authors concluded that the status of evidence for the effectiveness of these interventions is encouraging in both in terms of already conducted studies showing positive impacts and that several interventions are in the process of performing more rigorous and large scale randomized controlled trials.

Take Away Messages

- Stigma and discrimination are still important aspects of the lives of people with mental illness with negative consequences in a number of life domains.
- The stigma issue has been highlighted for several decades without any significant improvements in levels of stigma.
- A rather large number of anti-stigma programmes have been launched; although rather few have been systematically investigated which calls for future methodologically strong studies to settle the evidence base for specific interventions.
- Self-stigma derived from public stigma is also quite prevalent with negative life consequences for those afflicted. A conclusion is that although anti-stigma campaigns focusing the public may be of some value they must be accompanied by interventions to address self-stigma and anticipated discrimination.
- The scientific literature on anti self-stigma interventions is scarce and it is an urgent task to develop such interventions and investigate their evidence.
- Some candidate areas of intervention against self-stigma have been proposed, including psychoeducative approaches, CBT oriented approaches and reduction of self-stigma via disclosure.
- Current main activities
 - (a) Time To Change campaign in England: <http://www.time-to-change.org.uk/>
 - (b) The Opening minds campaign in Canada: <http://www.mentalhealthcommission.ca/English/initiatives/11874/opening-minds>
 - (c) The See Me campaign in Scotland: <https://www.seemescotland.org/>
 - (d) The Global Alliance Against Stigma: <http://www.time-to-change.org.uk/globalalliance>
 - (e) Shatter the stigma on World health day 2016: http://www.mhe-sme.org/fileadmin/Position_papers/Joint_Press_Release_-_WHD_MHE_ILGA.pdf

References

- Angermeyer, M., & Dietrich, S. (2006). Public beliefs about and attitudes towards people with mental illness: A review of population studies. *Acta Psychiatrica Scandinavica*, *113*, 163–179.
- Brockington, I., Hall, P., Levings, J., & Murphy, C. (1993). The community's tolerance of the mentally ill. *British Journal of Psychiatry*, *162*, 93–99.
- Brohan, D., Elgie, R., Sartorius, N., & Thornicroft, G. (2010). Level of Self-stigma, empowerment and perceived discrimination among people with schizophrenia in 14 European countries the GAMIAN: Europe studies. *Schizophrenia Research*, *122*, 232–238.
- Brohan, D., Gauci, D., Sartorius, N., Thornicroft, G., & For the GAMIAN–Europe Study Group. (2011). Self-stigma, empowerment and perceived discrimination among people with bipolar disorder or depression in 13 European countries: The GAMIAN–Europe study. *Journal of Affective Disorders*, *129*, 56–63.
- Corrigan, P. W., Watson, A. C., & Barr, L. (2006). The self-stigma of mental illness: implications for self-esteem and self-efficacy. *Journal of Social and Clinical Psychology*, *25*, 875–884.
- Corrigan, C. W., Morris, S. B., Michaels, P. J., Rafacz, J. D., & Rüsck, N. (2012). Challenging the public stigma of mental illness: A meta-analysis of outcome studies. *Psychiatric services*, *63*, 963–973.
- Corrigan, C. W., Druss, B. G., & Perlick, D. A. (2014). The impact of mental illness stigma on seeking and participating in mental health care. *Psychological Science in the Public Interest*, *15* (2), 37–70.
- Crisp, A. H., Gelder, A. G., Rix, S., Meltzer, H. I., & Rowlands, O. J. (2000). Stigmatisation of people with mental illnesses. *British Journal of Psychiatry*, *177*, 4–7.
- Fabrega, H. (1991). Psychiatric stigma in non-western countries. *Comprehensive Psychiatry*, *32*, 534–551.
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. New Jersey: Prentice-Hall.
- Gulliver, A., Griffiths, K. M., & Christensen, H. (2010). Perceived barriers and facilitators to mental health help-seeking in young people: A systematic review. *BMC Psychiatry*, *10*, 113. doi:10.1186/1471-244X-10-113.
- Hansson, L., Stjernswärd, S., & Svensson, B. (2014). Perceived and anticipated discrimination in people with mental illness—An interview study. *Nordic Journal of Psychiatry*, *68*, 100–106.
- Hansson, L., Stjernswärd, S., & Svensson, B. (2016). Changes in attitudes, intended behaviour and mental health literacy in the Swedish population 2009–2014. An evaluation of a national anti-stigma campaign. *Acta Psychiatrica Scandinavica*, *134* (Suppl. 446): 71–79.
- Heather, S., & Arboleda-Florez, J. (2001). Community attitudes toward persons with schizophrenia. *Canadian Journal of Psychiatry*, *46*(3), 245–252.
- Henderson, C., Robinson, E., Evans-Lacko, S., Corker, E., Rebollo-Mesa, I., & Rose, D. (2016). Public knowledge, attitudes, social distance and reported contact regarding people with mental illness 2009–2015. *Acta Psychiatrica Scandinavica*, *134*(Suppl. 446), 23–33.
- Jorm, A. F., Christensen, H., & Griffiths, K. M. (2005). The impact of Beyondblue: the national depression initiative on the Australian public's recognition of depression and beliefs about treatments. *Australian and New Zealand Journal of Psychiatry*, *39*, 248–254.
- Kuipers, E., Yesufu-Udechuku, A., Taylor, C., & Kendall, T. (2014). Management of psychosis and schizophrenia in adults: Summary of updated NICE guidance. *British Medical Journal*, *348*, g1173.
- Link, B. G., Cullen, F. T., Struening, E., Shrout, P. E., & Dohrenwend, B. P. (1989). A modified labelling theory approach in the area of mental disorders; An empirical assessment. *American Sociology Review*, *54*, 400–423.
- Link, B. G., & Phelan, J. C. (2001). Conceptualizing stigma. *Annual Review of Sociology*, *27*, 363–385.

- Livingston, J. D., & Boyd, J. E. (2010). Correlates and consequences of internalized stigma for people living with mental illness: a systematic review and meta-analysis. *Social Science and Medicine*, *71*, 2150–2161.
- Mittal, D., Sullivan, G., Chekuri, L., Allee, E., & Corrigan, P. W. (2012). Empirical studies of self-stigma reduction strategies: A critical review of the literature. *Psychiatric Services*, *63*, 974–981.
- Pescosolido, B. A. (2013). The public stigma of mental illness: What do we think; what do we know; What can we prove? *Journal of Health and Social Behavior*, *54*(1), 1–21.
- Schomerus, G., Schwahn, C., Holzinger, A., Corrigan, P. W., Grabe, H. J., Carta, M. G., et al. (2012). Evolution of public attitudes about mental illness: a systematic review and meta-analysis. *Acta Psychiatrica Scandinavica*, *125*, 440–452.
- Schulze, B. (2007). Stigma and mental health professionals: A review of the evidence on an intricate relationship. *International Review of Psychiatry*, *19*, 137–155.
- Sharac, J., McCrone, P., Clement, S., & Thornicroft, G. (2010). The economic impact of mental health stigma and discrimination: A systematic review. *Epidemiologia e Psichiatria Sociale*, *19*, 223–232.
- Thornicroft, G. (2006). *Shunned: discrimination against people with mental illness*. Oxford: Oxford University Press.
- Thornicroft, G., Rose, D., & Kassam, A. (2007). Discrimination in health care against people with mental illness. *International Review of Psychiatry*, *19*, 113–122.
- Thornicroft, G., Brohan, E., Rose, D., Sartorius, N., Leese, M., & The INDIGO Study Group. (2009). Global pattern of experienced and anticipated discrimination against people with schizophrenia: A cross-sectional survey. *Lancet*, *373*, 408–415.
- Thornicroft, G., Mehta, N., Clement, S., Evans-Lacko, S., Doherty, M., Rose, D., et al. (2016). Evidence for effective interventions to reduce mental-health-related stigma and discrimination. *Lancet*, *387*, 1123–1132.
- Yanos, P. T., Rosenfield, S., & Horwitz, A. V. (2001). Negative and supportive social interactions and quality of life among persons diagnosed with severe mental illness. *Community Mental Health Journal*, *37*, 405–419.
- Yanos, P. T., Lucksted, A., Drapalski, A. L., Roe, D., & Lysaker, P. (2015). Interventions targeting mental health self-stigma: A review and comparison. *Psychiatric Rehabilitation Journal*, *38*(2), 171–178.