Memorandum
Understanding and overcoming the stigma of substance use disorders

Georg Schomerus[1], Alexandra Bauch[1], Bernice Elger[2,3], Sara Evans-Lacko[4], Ulrich Frischknecht[5], Harald Klingemann[6], Ludwig Kraus[7,8], Regina Kostrzewa[9], Jakob Rheinländer[10], Christina Rummel[11], Wiebke Schneider[12], Sven Speerforck[1], Susanne Stolzenburg[1], Elke Sylvester[13], Michael Tremmel[14], Irmgard Vogt[15], Laura Williamson[16], Annemarie Heberlein[17], Hans-Jürgen Rumpf[18,19]

1 Klinik und Poliklinik für Psychiatrie und Psychotherapie, Universitätsmedizin Greifswald, Greifswald
2 Centre universitaire romand de médecine légale, Université de Genève,
3 Insititut für Bio- und Medizinethik, Universität Basel
4 London School of Economics, London
5 Klinik für Abhängiges Verhalten und Suchtmedizin, Zentralinstitut für Seelische Gesundheit, Medizinische Fakultät Mannheim, Universität Heidelberg
6 HKB Hochschule der Künste Bern, Forschungsbereich Kommunikationsdesign
7 IFT Institut für Therapieforschung, München
8 Centre for Social Research on Alcohol and Drugs, Stockholm University, Stockholm, Sweden
9 Medical School Hamburg, Department of family, child and social work, Hamburg
10 Hamburg
11 Hamm
12 Guttempler Deutschland, Hamburg
13 Fachklinik Nettetal, Caritasverband für die Diözese Osnabrück e.V., Osnabrück
14 Kreuzbund e.V. Selbsthilfe und Helfergemeinschaft für Suchtkranke und Angehörige, Hamm
15 Institut für Suchtforschung, Frankfurt University of Applied Sciences, Frankfurt
16 Pennsylvania State University, University Park, Pennsylvania, USA
17 Fachklinikum Uchtspringe, Stendal
18 Klinik für Psychiatrie, Universität Lübeck
19 Deutsche Gesellschaft für Suchtforschung und Suchttherapie (DG Sucht)

Gefördert durch:

Bundesministerium für Gesundheit

aufgrund eines Beschlusses des Deutschen Bundestages

Translation from the German version (http://www.dg-sucht.de/fileadmin/user_upload/pdf/aktuelles/Memorandum_Stigmatisierung.pdf)

In Cooperation with the German Society for Addiction Research and Addiction Therapy (DG Sucht)

Abstract

1. Background

Stigma does harm to individuals with substance use disorders (SUD), and it increases the burden of SUDs. It presents a barrier to help seeking, results in lower treatment quality and increases social and health related consequences of SUDs. This applies to both the individual, societal and economic consequences of substance use. Moreover, stigmatizing persons with addictions is an ethical problem, since it discriminates against a certain group, infringes on their human dignity and takes away their rights in many areas of life.

Dealing with substance use disorders without stigma is possible. Eliminating the stigma of SUDs means finding better ways to deal with SUDs and to make these ways available to everyone. Instead of devaluing, marginalizing and disciplining persons with SUD, empowerment and appreciation need to be at the core of dealing with SUD in prevention, treatment and every day life.

2. Recommendations

Improving the quality of SUD care and prevention

Structural discrimination needs to be addressed by structural measures. Examples are increasing the availability of psychotherapy for persons with SUD, or improving the care of co-morbid somatic illnesses. Courses on **anti-stigma competence** need to be implemented in the training of all healthcare professions. All **prevention activities need to be routinely checked** for possible stigmatizing side-effects (for example, when deterrence is used as a strategy). It is necessary to **develop and evaluate strategies that increase the acceptance of early recognition of substance use problems**, e.g. embedding substance related early interventions into **integrated behavioral prevention approaches** that refer to different health and risk behavior. The **separation of addiction services within the health care system must be overcome**.

Empowerment

All anti-stigma efforts need to be led by people with SUD.

Persons with SUD and their families need to be empowered **to stand up against devaluation and discrimination**. To respect the dignity of individuals with SUD it is necessary to create accepted, safe, legitimate and functional **spaces for substances use**.

Communication and Coordination

Existing structures should be used and strengthened to provide a platform for anti-stigma work and to facilitate joint efforts of persons with SUD, relatives and professionals. To make the overarching message visible, **joint public relations work and communication** across several projects is necessary. A **report** detailing anti-stigma efforts and their results needs to be compiled on a regular basis. A **media guide** to facilitate stigma-free reporting on SUD should be created.

Research

Research on the consequences of stigma and on strategies for de-stigmatization needs to be promoted. Research is required on the population level in order to assess and monitor the cultural reality of stigma. It is also required on the individual level to study specific consequences of stigma. Persons with SUD well as relatives should participate in this research.

Developing concepts and the legal framework

The legal preconditions and consequences of substance use require a continuous review for stigmatizing effects. Efforts should be made to decriminalize substance use and implement stigma-free prevention. It is necessary to further develop the **illness concept of SUD**, so that this concept

contributes to reducing barriers to help, allows for non-stigmatizing early interventions, accounts for the continuum of substance use, and, at the same time, provides the protection offered by a diagnosis. This concept needs to bridge medical and social perspectives on SUD and should lay a conceptual groundwork for dealing with SUD without stigma.

I. Preambel

Substance use disorders (SUD) are common and affect persons from all social backgrounds. Nonetheless, people with SUD and their relatives are marginalized and heavily stigmatized. Stigma increases addiction problems and makes life more difficult for those affected. Aim of this memorandum is to show how the stigma of substance use disorders can be understood and overcome.

Stigma has been conceptualized as a process, where a specific feature, for instance a substance use disorder, triggers labeling of a person and linking the person to negative stereotypes. Eventually, this results in devaluation and discrimination. Stigma occurs in many ways: it is experienced, perceived as a threat or avoided by keeping a condition secret. It does not only occur in interpersonal contact (public stigma), but also manifests itself in discriminating structures and regulations (structural stigma). Personal attitudes may result in discrimination of others, but also in self-stigmatization once a person has come to terms with his/her own substance use problems.

This memorandum is the result of a one-week closed workshop in September 2016, which was held by the Department of Psychiatry of Greifswald University, in collaboration with the German Society for Addiction Research and Addiction Therapy (DG-Sucht). It was funded by the Federal Ministry of Health (Bundesgesundheitsministerium). Workshop participants were from a wide range of different areas, such as self-help, health promotion and prevention, addiction care, rehabilitation, psychiatry, psychotherapy, sociology, ethics, epidemiology, media and stigma research. First results of the meeting were discussed during a public panel debate, which in turn informed this memorandum. This memorandum is about substance use disorders and problems related to addiction, but we also enlarge upon conceptional questions regarding the distinction between health and illness as well as upon the use of appropriate terms for problems in the field of craving, addiction, and substance, which is still lacking a satisfactory solution. This memorandum refers to substance use disorders, even though several of the points mentioned are also applicable to behavioral addictions.

II. Stigma hurts persons with SUD and further enhances addiction related problems

International population studies show that the stigma of SUDs, when compared to other mental disorders, is dominated by stronger feelings of blame, less acceptance of a disease model of SUDs, and stronger rejection of persons with SUD. Rejection and devaluation serve as a signal to persons with SUD that their behavior is not acceptable, and that they are not tolerated within the personal sphere of other persons. In fact, SUDs can cause considerable damage to the lives of persons with SUD, to their relatives and to their social environment. Since blame plays an important role for the stigma of SUD, this points to a **strong normative and moral connotation** of SUD stigma. Stigmatizing persons with SUD can be understood as an attempt to resolve the problem of addiction through taboo, marginalization and devaluation, or to make the problem manageable, at least. However, this approach is dysfunctional, since it does not reduce the problem, but increases it.

In fact, **stigma makes changing substance use behavior more difficult**. Funding the treatment of SUDs has low priority among the public compared to the treatment of other health problems. Stigma of SUD

isolates persons who need help, and devalues those who need power and self-confidence in order to deal with a severe problem. This also applies to their families. The more severely people are affected by SUD, the more vulnerable they are, and the more help they need; but simultaneously, they and their families face even stronger exclusion and discrimination. Studies show that self-stigma weakens drinking-refusal self-efficacy, that experienced and anticipated stigma increase symptom burden, and that treatment and help are avoided to avoid stigma. Stigmatizing persons with SUD does not solve any problems, it only aggravates them.

Exclusion and discrimination of persons with SUD and of their relatives happen in many areas of every day life, the following account does thus not claim to be exhaustive, it rather illustrates the complexity of the problem. Within the health care system, persons seeking help for a SUD in an emergency department or seeking other medical care frequently experience derogatory treatment by medical staff. Therefore, many persons avoid or delay help-seeking for fear of being stigmatized.

Persons with SUD are also discriminated against with respect to **access** to out-patient psychotherapy and **funding** of hospital stays by their health insurance when compared to people with other mental illnesses. **Health promotion and prevention** can increase stigma and devalue and marginalize those affected, for instance when presenting extremely severe cases in ordert to scare people off using substances. The primary preventive effect of such strategies is questionable, while instead such exaggeration and enforcement of stereotypes is doing harm to the stigmatized minority. At the **work place**, the stigma of SUD is a huge barrier to helpfully addressing substance use problems at an early stage by colleagues or supervisors, or to disclosure by the person affected. By not talking about substance use problems, they are protracted and amplified. Persons with SUD are often condescendingly treated by **institutions,** for instance within the legal system or in social and health care. Reports about negative consequences of addiction usually dominate the **images of SUD in the media**, while recovery remains invisible. Favorable outcomes (sometimes without professional help) are concealed by those concerned for fear of being stigmatized. Beyond, the fact that many substances are illegal also contributes to the stigmatization of those who use them.

Stigma hits hardest on those who are already disadvantaged for other reasons: Persons with other mental disorders, low income or few personal resources are easier marginalized and less likely able to defend themselves against it. Particularly vulnerable groups for the consequences of stigma include women, who are often poorly reached by existing addiction care programs, or persons belonging to a sexual minority ("LGBT-Communities"), or cultural / ethnic minorities.

Stigma is not only an **individual problem** for persons with SUD and their relatives. It is also a **public health issue**, because it increases the burden of SUD and causes substantial, preventable costs. Also, stigma is an **ethical problem**, because the group of persons with SUD is discriminated against and treated unfairly. Last but not least, stigma violates the **human dignity** of those concerned. Stigma is an **injustice** done to persons with SUD, harming them in many areas of life, for example with respect to work, education, and independent living.

III. Dealing with SUD in a better way - without stigma, for the person

De-stigmatization does not mean to trivialize problems related to substance use and addiction, but to find better solutions for them and to make these solutions widely available. De-stigmatization can only succeed if we find an alternative and better way of dealing with SUD. Not devaluation, marginalization and disciplining, but **appreciation and empowerment** need to be at the heart of prevention, treatment and the everyday dealing with SUD. Many current developments in addiction care are already moving along these lines and are thereby contributing to de-stigmatization. Examples include *Motivational Interviewing* and the *Community Reinforcement Approach*. Because many persons with SUD are marginalized for more than one reasons, de-stigmatization of SUD is a part of **a joint effort to fight against the discrimination of underprivileged groups in society**. Finally, fighting stigma will gradually allow individuals with SUD **to stand up for their rights,** because disclosing a SUD will become easier. Disclosure, in turn, will further decrease stigma.

<u>How could we deal with SUD without stigma?</u>

To delineate what can be achieved when de-stigmatizing SUD, we developed a vision of dealing with SUD without stigma.

In this scenario, a **respectful, unprejudiced encounter** with those seeking help facilitates the access to treatment at first contact and beyond. From prevention to follow-up care, help is offered without blame or paternalism. The guiding principle of help is not disciplining and control, but support, respect, facilitating autonomy as well as self responsibility. Self-help programs focus on individual strengths to diminish self-stigma. A stigma-free handling of SUD respects the human dignity of persons with SUD as well as of their relatives at all times.

Since SUD tend to occur together with other mental and physical diseases, **care is offered in one general system.** The unrealistic separation by substances as well as the segregation in addiction care, medical/psychiatric help and psychotherapy is abandoned in favor of a comprehensive help system. Individuals with SUD are treated exactly the same way as any other person for their mental and medical co-morbidities. Converging the different help systems enables a holistic view on health behavior; it does not reduce it to addiction problems or even a single substance.

The scenario also includes conceptual developments. A stigma-free handling of SUD requires an illness concept that offers the protection of a diagnosis, but simultaneously does not devalue the person, allows for recovery and transitions, and strengthens individual autonomy. **An active disease concept of SUD** needs to refer to a continuum of mental illness and health, for instance by taking into account a continuous measure like the quantity of substance use. It needs to offer a gradual view on mild and severe stages, to be of help for people with all degrees of substance related problems and facilitate early interventions instead of deterring people. **Diagnoses must not stick to a person for life**, but accompany them as long as they are helpful. An active disease concept includes the expectation of active participation from the side of the person with SUD, and thereby strengthens self-efficacy and activates processes of self-healing. Active participation of persons with SUD relies on personal

resources and available support of the social network. If these are scarce, society needs to compensate for this.

Since blame is at the heart of SUD stigma, it is necessary to arrive at **a differentiated view of individual responsibility** of persons with SUD. A non-stigmatizing concept of responsibility takes into account that both the individual and the social environment have to take responsibility to overcome a SUD. The **relation of individual and social responsibility is dynamic**, because in the course of a SUD the ability to take individual responsibility can be impaired temporarily and to various degrees. It is then the social responsibility of the personal environment and society at large to offer support, encouragement and resources in order to enable the person to better take individual responsibility again.

IV. Recommendations

To achieve the goal of dealing with SUD without stigma, we make the following recommendations, which group into five areas: empowerment, qualitative improvement of care, conceptual and legal developments, research, coordination and communication of anti-stigma activities.

Improving the quality of health care and prevention

Structural discrimination needs to be addressed by structural measures. Examples are increasing the availability of psychotherapy for persons with substance use disorders, or improving the care of comorbid somatic illnesses.

Courses on **anti-stigma competence** need to be implemented in the training of all healthcare professionals. These courses need to be led by people with lived experiences.

All **prevention activities need to be routinely checked for** possible stigmatizing side-effects. This routine check needs to include feedback from people with lived experience about the way their disorder and the group of persons with SUD is portrayed.

It is necessary to **develop and evaluate strategies that increase the acceptance of early recognition of substance use problems**, e.g. embedding substance related early intervention strategies into **integrated behavioral prevention approaches** that refer to different health and risk behavior.

The **separation of addiction services within the health care system needs to be overcome**.

Empowerment

Persons with SUD and their families need to be empowered **to stand up against devaluation and discrimination**. The topic of discrimination should be routinely taken up in **addiction counseling**. Guidelines should be developed that help counsellors and clients to **identify discrimination** and, where necessary, **to take legal steps against individual and structural discrimination**.

To preserve the dignity of individuals with SUD, and in order to stop a constant re-inforcement of negative stereotypes, it is necessary to create accepted, save, legitimate and functional **spaces for substances use.**

Communication and Coordination

Existing structures should be used and strengthened to provide a platform for anti-stigma work and to facilitate joint efforts of persons with SUD, relatives and professionals.

To make the overarching message visible, **joint public relations work and communication** across several projects is necessary.

A **report** detailing anti-stigma efforts and their results needs to be compiled on a regular basis.

A **media guide** to facilitate stigma-free reporting on SUD should be created.

Advancing illness concepts and legal conditions

The legal preconditions and consequences of substance use require a continuous review for stigmatizing effects. Efforts should be made to decriminalize substance use and implement stigma-free prevention.

It is necessary to further develop the **illness concept of SUD**, so that this concept contributes to reducing barriers to help, allows for non-stigmatizing early interventions, accounts for the continuum of substance use, and, at the same time, provides the protection offered by a diagnosis. This concept needs to bridge medical and social perspectives on SUD and should lay a conceptual groundwork for dealing with SUD without stigma.

Research

Research on the consequences of stigma and on strategies for de-stigmatization needs to be promoted. Research is required on the population level in order to assess and monitor the cultural reality of stigma. It is also required on the individual level to study specific consequences of stigma. Persons with SUD as well as relatives should participate in this research.

Research on mental disorders and SUD, including their social causes and consequences as well as the role of stigmatization for the course of the diseases and for treatment should be **jointly** advanced. Parity of funding with research on medical disorders that pose a similar burden on public health needs to be accomplished.

Persons with SUD and their relatives need to be involved in research. A useful model is community based participatory research (CBPR).

Literature (Selection)

Corrigan, P., Schomerus, G., Shuman, V., Kraus, D., Perlick, D., Harnish, A., Kulesza, M., Kane-Willis, K., Qin, S. & Smelson, D. (2016). Developing a research agenda for understanding the stigma of addictions Part I: Lessons from the Mental Health Stigma Literature. *Am J Addict. 2017 Jan;26(1):59-66.*

Evans-Lacko, S., Malcolm, E., West, K., Rose, D., London, J., Rusch, N., Little, K., Henderson, C. & Thornicroft, G. (2013). Influence of Time to Change's social marketing interventions on stigma in England 2009-2011. *Br J Psychiatry Suppl* **55**, s77-88.

Freimüller, L. & Wölwer, W. (2012). *Antistigma-Kompetenz in der psychiatrisch-psychotherapeutischen und psychosozialen Praxis: das Trainingsmanual; mit 3 Tabellen*. Schattauer Verlag.

Klingemann, H., Sobell, L. (Hrsg.) (2006) Selbstheilung von der Sucht. VS Sozialwissenschaften, Wiesbaden.

Klingemann H, Sobell MB, Sobell LC. (2010): Continuities and changes in self-change research. Addiction, 105(9):1510-8.

Rehm, J., Marmet, S., Anderson, P., Gual, A., Kraus, L., Nutt, D. J., ... & Wiers, R. W. (2013). Defining substance use disorders: do we really need more than heavy use?. Alcohol and alcoholism, 48(6), 633-640.

Room, R. (2001). Intoxication and bad behaviour: understanding cultural differences in the link. *Soc Sci Med* 53, 189-98.

Rüsch, N., Abbruzzese, E., Hagedorn, E., Hartenhauer, D., Kaufmann, I., Curschellas, J., Ventling, S., Zuaboni, G., Bridler, R., Olschewski, M., Kawohl, W., Rossler, W., Kleim, B. & Corrigan, P. W. (2014). Efficacy of Coming Out Proud to reduce stigma's impact among people with mental illness: pilot randomised controlled trial. *Br J Psychiatry* **204**, 391-7.

Schomerus, G., Lucht, M., Holzinger, A., Matschinger, H., Carta, M. G. & Angermeyer, M. C. (2011). The Stigma of Alcohol Dependence Compared with Other Mental Disorders: A Review of Population Studies. *Alcohol Alcohol* **46**, 105-112.

Schomerus, G., Matschinger, H. & Angermeyer, M. C. (2006). Preferences of the public regarding cutbacks in expenditure for patient care: Are there indications of discrimination against those with mental disorders? *Social Psychiatry and Psychiatric Epidemiology* **41**, 369-377.

Stadt Zürich (2012). Stigmatisierung - Zum Umgang mit Risiken und Nebenwirkungen der Suchtprävention. https://www.stadt-zuerich.ch/content/dam/stzh/ssd/Deutsch/Gesundheit%20Praevention/Suchtpraevention/Publikationen%20und%20Broschueren/Grundlagenpapiere/12.07.12_stigma.pdf

Williamson, L., Thom, B., Stimson, G. V. & Uhl, A. (2014). Stigma as a public health tool: implications for health promotion and citizen involvement. *Int J Drug Policy* **25**, 333-5.