Mental health stigma and discrimination: discussion paper for the drafting group[1]

Purpose and introduction

The purpose of this document is to provide background information on mental health related stigma and discrimination. It has been developed for the drafting group on stigma under the Mental Health Subgroup of the Public Health Expert Group. Authors from the NIMH, Czech Republic[1] have prepared this document for review for the other Member States representatives in the drafting group. This paper is expected to provide a basis for discussion and in highlighting the key areas that would need to be considered to ensure that stigma and discrimination are addressed in national and EU level policy making, project development and implementation of actions in mental health.

This discussion paper supports the work of the Expert Group on Public Health (PHEG) and its subgroup on mental health in the context of the implementation of the flagship #18 of the Commission Communication on a comprehensive approach to mental health[2] adopted in June 2023 as well as Member States in setting up collaboration across sectors.

Mental health stigma

Stigma related to mental health conditions is widely recognized as consisting of three components: (i) problems of knowledge, primarily due to a lack of awareness and understanding; (ii) negative attitudes, or prejudice; and (iii); negative behaviour, or discrimination[3]. However, it is important to differentiate between stigma (negative attitudes or prejudice) and its negative consequences (negative behaviour or discrimination).

Existing evidence suggests that although mental health stigma is linked to a wide range of negative outcomes, the association is often correlational rather than causal between negative attitudes and discriminatory behaviour. Also, it has not been established that positive change in stigma (beliefs and

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[2] https://health.ec.europa.eu/document/download/cef45b6d-a871-44d5-9d62-3cecc47eda89_en?filename=com_2023_298_1_act_en.pdf

[3] Thornicroft G, Sunkel C, Alikhon Aliev A, Baker S, Brohan E, El Chammay R, Davies K, Demissie M, Duncan J, Fekadu W, Gronholm PC, Guerrero Z, Gurung D, Habtamu K, Hanlon C, Heim E, Henderson C, Hijazi Z, Hoffman C, Hosny N, Huang FX, Kline S, Kohrt BA, Lempp H, Li J, London E, Ma N, Mak WWS, Makhmud A, Maulik PK, Milenova M, Morales Cano G, Ouali U, Parry S, Rangaswamy T, Rüsch N, Sabri T, Sartorius N, Schulze M, Stuart H, Taylor Salisbury T, Vera San Juan N, Votruba N, Winkler P. The Lancet Commission on ending stigma and discrimination in mental health. Lancet. 2022 Oct 22;400(10361):1438-1480.

attitudes) brings about reduced discrimination[4]. Indeed, most studies aiming to reduce mental health stigma primarily measure changes in beliefs and attitudes at the individual level. These studies often fail to investigate whether improved public attitudes result in tangible benefits to people living with mental health conditions such as increased funding for mental health care, improved housing, or increased inclusion in the labour market[5].

In this context, we can differentiate between public stigma, self-stigma, and stigma by association. Public stigma refers to inaccurate knowledge or negative attitudes held by wider society (e.g. believing that people with mental health conditions are primarily to blame for their conditions). Self-stigma is the internalization of these negative societal attitudes and prejudice, leading to self-identification with them. Stigma by association refers to the application of negative stereotypes and discrimination towards family members (e.g., attributing a condition to a moral failure of family members) or mental health professionals (e.g., negatively valuing mental health professions because of their association with people with mental health conditions) [6]. Additionally, the term 'structural, systemic, or institutional stigma' is often used to describe policies and practices that disadvantage a stigmatized group, whether intentionally or unintentionally.[3] However, from the perspective used in this paper, this definition aligns more with structural discrimination (unfair practices) rather than stigma (a societal label). Therefore, it is discussed below under the section on discrimination.

Implications for policy and interventions

Countries face challenges in resource allocation and the potential impact of actions. Therefore, it is essential to adopt an evidence-based approach in stigma policy making and research to better inform prioritisation and facilitate targeted and effective interventions. This approach can improve the lives of individuals with lived experience of mental health conditions and promote a more equitable society for all.

The Lancet Commission on ending stigma and discrimination in mental health[3] has (similarly to prior studies and reviews) conceptualized discrimination as part of stigma. This conceptualization overcomes the lack of evidence linking stigma as a societal label that leads to prejudice and negative attitudes directly (causally) to discrimination, which leads to reduced life chances. This conceptualization has limitations and there is a need for future evidence informed approaches to distinguish nuances in the relationships between stigma and discrimination and their consequences.

European countries are encouraged to focus on a universal and human-rights oriented approach in mental health. The aim should be on substantially improving the ability of all, including those with mental health

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[4] Clement S, Lassman F, Barley E, Evans-Lacko S, Williams P, Yamaguchi S, Slade M, Rüsch N, Thornicroft G. Mass media interventions for reducing mental health-related stigma. Cochrane Database Syst Rev. 2013 Jul 23;2013(7):CD009453.

[5] Voldby KG, Hellström LC, Berg ME, Eplov LF. Structural discrimination against people with mental illness; a scoping review. SSM - Mental Health 2022;2:100117

[6] Thornicroft G, Sunkel C, Alikhon Aliev A, Baker S, Brohan E, El Chammay R, Davies K, Demissie M, Duncan J, Fekadu W, Gronholm PC, Guerrero Z, Gurung D, Habtamu K, Hanlon C, Heim E, Henderson C, Hijazi Z, Hoffman C, Hosny N, Huang FX, Kline S, Kohrt BA, Lempp H, Li J, London E, Ma N, Mak WWS, Makhmud A, Maulik PK, Milenova M, Morales Cano G, Ouali U, Parry S, Rangaswamy T, Rüsch N, Sabri T, Sartorius N, Schulze M, Stuart H, Taylor Salisbury T, Vera San Juan N, Votruba N, Winkler P. The Lancet Commission on ending stigma and discrimination in mental health. Lancet. 2022 Oct 22;400(10361):1438-1480.

conditions, to take actions that promote and protect mental health as well as promote inclusion and equal opportunities for full social participation.

This is expected to lead to strengthening evidence-based actions in three areas: tackling discrimination and promote inclusion of people with mental health conditions; reducing self-stigma of people with mental health conditions and their loved ones; and mental health literacy and resilience.

Tackling Discrimination and Social Exclusion of People with Mental Health Conditions

People with mental health conditions often face discrimination, which limits their access to employment, housing, health care, social activities and other essential services. To combat this, evidence-based programmes[7] should be supported to help these individuals live independently in their communities and be able to meaningfully contribute to them. In the context of employment, there are approaches that have proven effective in securing jobs for people with mental health conditions[8].

Addressing stigma has brought advancements globally. However individual behavioural and system level change still needs to be enhanced.

Addressing inequalities in health care would require a series of actions ranging from comprehensive strategies, including increased financing, enhanced training for health care professionals, implementing person-centred and rights-based mental health care, and allowing people with mental health conditions to exercise their rights as outlined in the Convention on the Rights of Persons with Disabilities[9]. Currently, the average spending on mental health is around 4% (the government's total expenditure on mental health as % of total government health expenditure) in central and eastern EU countries and 9% in western EU countries, while mental health conditions account for 15-20% of the overall disease burden as expressed by disability adjust life years[10]. This contributes to the increase in inequalities for access to and availability of mental health services in particular in countries where mental health care still relies largely on traditional psychiatric hospitals.

Central to these efforts are people with lived experience of mental health conditions, who can play a crucial role in educating professionals, advocating for themselves and others, enforcing CRPD rights, and participating in decision-making processes. Integrating people with lived experience as peer lecturers and care workers, involving them in all relevant policy decisions, and recognizing their participation and experience-based knowledge can significantly improve services, enhance mental health support and reduce stigma. People with lived experience need opportunities and resources for meaningful involvement, respectful environments, and comprehensive education to contribute effectively[11].

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[7] An example is Housing First: 2019-10-10-HFinEurope_Report2019_Summary.pdf (housingfirsteurope.eu)
[8] An example is Individual Placement and Support (IPS): https://ipsworks.org/index.php/what-is-ips/
[9] https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities.
[10] Mental Health Atlas 2020: https://www.who.int/publications/i/item/9789240036703.
[11] Thornicroft G, Sunkel C, Alikhon Aliev A, Baker S, Brohan E, El Chammay R, Davies K, Demissie M, Duncan J, Fekadu W, Gronholm PC, Guerrero Z, Gurung D, Habtamu K, Hanlon C, Heim E, Henderson C, Hijazi Z, Hoffman C, Hosny N, Huang FX, Kline S, Kohrt BA, Lempp H, Li J, London E, Ma N, Mak WWS, Makhmud A, Maulik PK, Milenova M, Morales Cano G, Ouali U, Parry S, Rangaswamy T, Rüsch N, Sabri T, Sartorius N, Schulze M, Stuart H, Taylor Salisbury T, Vera

Addressing Self-Stigma

Self-stigma occurs when people with mental health conditions internalize negative stereotypes of others, agree with them, and turn them against themselves. Self-stigma may lead to giving up important life goals and to social isolation, and it is a barrier to recovery. Evidence-based interventions to combat self-stigma exist and should be promoted across the EU[12]. Additionally, there is evidence suggesting that high-quality psychoeducation can help reduce self-stigma. These interventions can empower individuals and their loved ones, improving their quality of life and social inclusion.

Enhancing Population Mental Health Literacy and Resilience

Currently, the evidence that mental health literacy programs directly influence behavioural outcomes, such as improved stress and symptom management or prevention of mental health conditions, is limited. However, this may largely be due to a misunderstanding of mental health literacy, resulting in a lack of high-quality studies[13]. In other fields of medicine, health literacy has been associated with positive behavioural effects[14], suggesting potential benefits for mental health if properly adopted.

Therefore, improving mental health literacy should be a cross-cutting theme in health policies and programmes. Mental health literacy program need to contain all four of the following components:

a) Knowledge and skills are essential to obtain and maintain good mental health.

b) Understanding of mental health issues and treatment and support options needs to be improved.

c) Positive attitudes towards mental health and exposure to the stories and experiences of individuals with lived experience is key to prevent and combat stigma. Personal stories should entail hope and recovery.

d) Ability and readiness to provide psychological support needs to be improved as well as ability to seek professional care when needed.

San Juan N, Votruba N, Winkler P. The Lancet Commission on ending stigma and discrimination in mental health. Lancet. 2022 Oct 22;400(10361):1438-1480.

[12] Rüsch, N., & Kösters, M. (2021). Honest, Open, Proud to support disclosure decisions and to decrease stigma's impact among people with mental illness: Conceptual review and meta-analysis of program efficacy. Social Psychiatry and Psychiatric Epidemiology, 56, 1513-1526.

[13] Kutcher, S., Wei, Y., & Coniglio, C. (2016). Mental health literacy: Past, present, and future. The Canadian Journal of Psychiatry, 61(3), 154-158.

[14] Berkman, N. D., Sheridan, S. L., Donahue, K. E., Halpern, D. J., & Crotty, K. (2011). Low health literacy and health outcomes: an updated systematic review. Annals of internal medicine, 155(2), 97-107.

Heine, M., Lategan, F., Erasmus, M., Lombaard, C. M., Mc Carthy, N., Olivier, J., ... & Hanekom, S. (2021). Health education interventions to promote health literacy in adults with selected non-communicable diseases living in low-to-middle income countries: a systematic review and meta-analysis. Journal of evaluation in clinical practice, 27(6), 1417-1428.

Chang, R. C., Yen, H., Heskett, K. M., & Yen, H. (2024). The Role of Health Literacy in Skin Cancer Preventative Behavior and Implications for Intervention: A Systematic Review. Journal of Prevention, 1-16.

Baccolini, V., Isonne, C., Salerno, C., Giffi, M., Migliara, G., Mazzalai, E., ... & Villari, P. (2022). The association between adherence to cancer screening programs and health literacy: A systematic review and meta-analysis. Preventive Medicine, 155, 106927

It would be important to make sure that the programs are available in educational, workplace and health care settings as well as online. Since stigma reduction is a component of mental health literacy interventions, comprehensive evidence-based mental health literacy programs are essential. These programs could also address the growing demand for human rights based mental health services through effective promotion, prevention, and early detection of mental health issues.

Special attention should be given to professional training for those in helping professions, such as social workers, teachers, healthcare professionals, peer support workers, and others who frequently work with individuals with mental health problems[14]. Additional special training on anti-stigma competence helps them reflect their role in the stigma process and actively contribute to public discourse and reduce social stigma.

Key Principles[15]

Firstly, it is important to promote the meaningful participation of people with lived experience of mental health conditions in decision-making processes and the planning and design of services, programmes, and interventions, ensuring use of ethical and participatory approaches that offer fair compensation and support for the expertise being provided. This is particularly crucial for reducing public mental health stigma, as social contact-based interventions have proven to be the most effective approach in this area. WHO is currently developing a roadmap to integrate lived experience into mental health services.

Secondly, to use positive, respectful, and non-derogatory language to avoid perpetuating stigma. This is a horizontal issue and should not only be limited to mental health policymaking but should be considered across all policy areas.

Thirdly, it is important to strengthen mental health advocacy groups and networks for people with lived experience. For this purpose, the European health policy platform by the European Commission provides an opportunity to connect across the EU on a virtual platform.

Fourthly, it is important to work with the media as they have a significant impact on mental health and suicide reporting. It is essential to work collaboratively with the media to ensure that reporting is accurate, sensitive and responsible. New initiatives are needed to tackle stigma in social media.

Finally, special attention should be given to intersectional stigma, where disadvantaged and vulnerable subgroups, such as migrants, refugees, the Roma population, LGBTQI+, people living with disabilities, and those in difficult socioeconomic or health situations, may face higher levels of stigma and its impacts.

Conclusions

Multifaceted and evidence-based approaches need to go beyond merely changing stigmatizing attitudes to ensure fully inclusive and supportive environments for people with mental health conditions. Stigma-focused initiatives should aim at eliminating institutionalised forms of unequal treatment, unequal

[14] Thornicroft G, Sunkel C, Alikhon Aliev A, Baker S, Brohan E, El Chammay R, Davies K, Demissie M, Duncan J, Fekadu W, Gronholm PC, Guerrero Z, Gurung D, Habtamu K, Hanlon C, Heim E, Henderson C, Hijazi Z, Hoffman C, Hosny N, Huang FX, Kline S, Kohrt BA, Lempp H, Li J, London E, Ma N, Mak WWS, Makhmud A, Maulik PK, Milenova M, Morales Cano G, Ouali U, Parry S, Rangaswamy T, Rüsch N, Sabri T, Sartorius N, Schulze M, Stuart H, Taylor Salisbury T, Vera San Juan N, Votruba N, Winkler P. The Lancet Commission on ending stigma and discrimination in mental health. Lancet. 2022 Oct 22;400(10361):1438-1480.

distribution of resources and discriminatory legislation, disrupting the ongoing reproduction of stigma especially through media, improving positive behaviours and decreasing discriminatory behaviours towards people with mental health issues and surrounding mental health.

Real change demands the public and systemic dismantling of harmful behaviours and discrimination that impede the rights of all people to pursue the highest attainable standard of mental well-being, and ensuring equitable access to mental health promotion, prevention of mental ill-health and care for all members of society, regardless of their mental health status.