#### NI<sup>M</sup>H NATIONAL INSTITUTE OF MENTAL HEALTH

# Stigma and discrimination in mental health

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# What is stigma?









# The Finnish flag stands for











# Czechs tasting the local beer while abroad on holiday:





# Stigma

# 'attribute, trait or disease that leads to any form of community sanction'

Goffman, E. Stigma: Notes on the management of spoiled identity. Simon and Schuster. 2009 [first published 1963].



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# The Lancet Commission on Ending Stigma and Discrimination in mental health

Slides courtesy of Sir Graham Thornicroft

### The Lancet Commissions

# **The Lancet** Commission on ending stigma and discrimination in mental health

Graham Thornicroft\*, Charlene Sunkel\*, Akmal Alikhon Aliev, Sue Baker, Elaine Brohan, Rabih el Chammay, Kelly Davies, Mekdes Demissie, Joshua Duncan, Wubalem Fekadu, Petra C Gronholm, Zoe Guerrero, Dristy Gurung, Kassahun Habtamu, Charlotte Hanlon, Eva Heim, Claire Henderson, Zeinab Hijazi, Claire Hoffman, Nadine Hosny, Fiona-Xiaofei Huang, Sarah Kline, Brandon A Kohrt, Heidi Lempp, Jie Li, Elisha London, Ning Ma, Winnie W S Mak, Akerke Makhmud, Pallab K Maulik, Maria Milenova, Guadalupe Morales Cano, Uta Ouali, Sarah Parry, Thara Rangaswamy, Nicolas Rüsch, Taha Sabri, Norman Sartorius, Marianne Schulze, Heather Stuart, Tatiana Taylor Salisbury, Norha Vera San Juan, Nicole Votruba, Petr Winkler

# Commission aims

- **Define** stigma and discrimination
- Summarise **impacts** of stigma & discrimination
- Review effectiveness of interventions
- Assess experience of large-scale programmes
- Understand the **roles of the media**
- **Recommendations** for action to end stigma

# Contributors to the Commission

- Co-produced by people with lived experience
- 22 Commissioners most from low- and middleincome countries
- 22 Members Commission Advisory Board
- Contributors from 26 countries worldwide
- Many poems and quotations

# **Defining Stigma**



## Impacts of stigma & discrimination

- contravenes **basic human rights**
- lead to marginalisation and social exclusion
- barrier to seeking help for mental health
- worse access to **physical health care**
- harms prospects for education and employment

# Global survey of people with lived experience

• 391 participants from 45 countries and territories

• **6 languages:** Arabic, Chinese, English, French, Russian and Spanish

• 65% respondents in **upper-middle income** countries

# Survey results

- PWLE should be **treated as well** as people with physical health conditions (93%)
- Stigma and discrimination negatively affect most people with mental health conditions (90%)
- Governments should invest in long-term national stigma programmes (83%)
- Stigma and discrimination **can be worse** than the impact of the mental health condition itself **(80%)**
- Media can make stigma and discrimination worse (71%)

### Effectiveness of interventions against stigma

- Overview 'umbrella review' of **216 systematic reviews**
- Core finding: **social contact** most effective intervention
- **Social contact:** direct or indirect contact for people who do and do not have experience of mental health conditions

### Roles of the media

- For bad: media play powerful roles in increasing stigma when they reinforce negative stereotypes
- e.g. someone is 'unpredictable' or 'dangerous'

- For good: media can decrease stigma when aligned with guidelines on responsible reporting
- e.g. WHO Guidelines on Reporting of Suicide

# Main message

People with lived experience are the **key active change agents** to reduce mental health stigma and discrimination via **social contact** 

# Stigmatization in Czechia



Contents lists available at ScienceDirect

European Psychiatry

journal homepage: http://www.europsy-journal.com

Original article

Reported and intended behaviour towards those with mental health problems in the Czech Republic and England

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#### ARTICLE INFO

#### ABSTRACT

Article history: Received 14 February 2015 Received in revised form 4 May 2015 Accepted 11 May 2015 Available online xxx

Keywords: Stigma Mental illness Social distance Central and Eastern Europe Post-communism This is one of the first studies, which compares the level of stigmatizing behaviour in countries that used to be on the opposite sides of the Iron Curtain. The aim was to identify the prevalence of reported and intended stigmatizing behaviour towards those with mental health problems in the Czech Republic and to compare these findings with the findings from England. The 8-item Reported and Intended Behaviour Scale (RIBS) was used to assess stigmatising behaviour among a representative sample of the Czech population (n = 1797). Results were compared with the findings of an analogous survey from England (n = 1720), which also used the RIBS. The extent of reported behaviour (i.e., past and present experiences with those with mental health problems) was lower in the Czech Republic than in England. While 12.7% of Czechs reported that they lived, 12.9% that they worked, and 15.3% that they were acquainted with someone who had mental health problems, the respective numbers for England were 18.5%, 26.3% and 32.5% (P < 0.001 in each of these items). On the other hand, the extent of intended stigmatizing behaviour towards those with mental health problems is considerably higher in the Czech Republic. Out of maximum 20 points attached to possible responses to the RIBS items 5-8, Czechs had a lower total score (x = 11.0, SD = 4.0) compared to English respondents (x = 16.1, SD = 3.6), indicating lower willingness to accept a person with mental health problems (P < 0.001). The prevalence of stigmatizing behaviour in the Czech Republic is worrying. Both, further research and evidence based anti-stigma interventions, should be pursued in order to better understand and decrease stigmatizing behaviour in the Czech Republic and possibly across the post-communist countries in Central and Eastern Europe. © 2015 Published by Elsevier Masson SAS.

#### P. Winkler et al. / European Psychiatry 30 (2015) 801–806

#### Table 3

Frequency of responses to items 5–8 on the RIBS questionnaire for the English and Czech sample; Chi<sup>2</sup> square test used to determine statistical significance.

Intended behaviour	Strongly agree n (%)	Agree n (%)	No agree nor disagree n (%)	Disagree n (%)	Strongly disagree n (%)	Don't know n (%)	Sig. England vs. Czechia
5. In the future, I wou	ld be willing to live	with someone	with a mental health prob	lem			
Eng.	541 (31.5)	421 (24.4)	422 (24.5)	123 (7.2)	140 (8.2)	73 (4.2)	<i>P</i> < 0.001
Czech	60 (3.3)	204 (11.3)	461 (25.6)	425 (23.6)	308 (17.2)	341 (19.0)	
6. In the future, I wou	ld be willing to wo	rk with someon	e with a mental health pro	blem			
Eng.	678 (39.4)	497 (28.9)	315 (18.3)	59 (3.4)	86 (5.0)	85 (4.9)	<i>P</i> < 0.001
Czech	79 (4.4)	274 (15.2)	444 (24.7)	364 (20.2)	281 (15.6)	357 (19.8)	
7. In the future, I wou	ld be willing to live	nearby to some	eone with a mental health	problem			
Eng.	713 (41.4)	521 (30.3)	330 (19.2)	51 (3.0)	55 (3.2)	51 (3.0)	<i>P</i> < 0.001
Czech	118 (6.6)	328 (18.2)	458 (25.5)	297 (16.5)	258 (14.3)	340 (18.9)	
8. In the future, I wou	ld be willing to con	tinue a relation	ship with a friend who dev	veloped a menta	al health problem		
Eng.	969 (56.3)	440 (25.6)	205 (11.9)	36 (2.1)	31 (1.8)	39 (2.3)	<i>P</i> < 0.001
Czech	142 (7.9)	349 (19.4)	489 (27.2)	253 (14.1)	222 (12.3)	344 (19.1)	

RIBS: Reported and Intended Behaviour Scale; Eng.: English; Sig.: significance.



# Development of public stigma toward people with mental health problems in Czechia 2013–2019

Published online by Cambridge University Press: 16 August 2021

Petr Winkler 🝺, Tomáš Formánek 🝺, Karolína Mladá and Sara Evans Lacko	Show author details $\checkmark$
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#### Abstract

#### Background

We aimed to assess the changes in public stigma towards people with mental health problems in Czechia; and to investigate the association between these and the exposure to the ongoing mental health care reform and one of its implementation projects focused on reducing stigma. • Attitudes and beliefs towards mental health and illness difficult to change even when large, evidence-based campaigns in place

European Psychiatry	Development of public stigma toward people
www.cambridge.org/epa	with mental health problems in Czechia 2013–2019
Research Article	Petr Winkler <sup>1,2*</sup> 🔊, Tomáš Formánek <sup>1,3</sup> 💿, Karolína Mladá <sup>1,4</sup> and Sara Evans Lacko <sup>5</sup>

Table 2. Linear regression models on differences in stigmatizing attitudes and intended behavior between 2013/2014 baseline and 2019.

	Intended b	ehavior (RIBS)	Attitu	des (CAMI)
	Crude model	Fully adjusted model	Crude model	Fully adjusted mode
Age	NA	0 (-0.01; 0.01)	NA	0.03 (0; 0.06)*
Gender				
Men	Reference	Reference	Reference	Reference
Women	NA	-0.38 (-0.65; -0.11)*	NA	2.08 (1.17; 2.99)**
Education				
Less than high school	Reference	Reference	Reference	Reference
High school or higher	NA	-0.48 (-0.75; -0.20)**	NA	1.52 (0.6; 2.44)**
Year				
2013	Reference	Reference	NA	NA
2014	NA	NA	Reference	Reference
2019	-0.06 (-0.34; 0.22)	-0.03 (-0.31; 0.25)	1.09 (0.15; 2.03)*	0.99 (0.06; 1.93)*

Note: \*p < 0.05; \*\* p < 0.001. The results are expressed as unstandardized beta coefficients with 33% cls. Post-stratification weights were applied to the analysis.





#### SSM - Mental Health

Available online 14 November 2024, 100369 In Press, Journal Pre-proof ⑦ What's this?



Changes in stigma and population mental health literacy before and after the Covid-19 pandemic: analyses of repeated cross-sectional studies

Petr Winkler <sup>1</sup> <sup>A</sup>, Benjamin Kunc <sup>2</sup>, Zoe Guerrero <sup>1</sup>, Pavel Mohr <sup>1</sup>, Georg Schomerus <sup>3</sup>, Karolína Mladá <sup>2</sup>

# Background

#### **Covid-19 pandemic**

- Detrimental effect on population mental health
- Increased interest in mental health across the population subgroups





 To assess changes in stigma and recognition of one's own mental health problems among the general adult non-institutionalized Czech population

# **Methods**

- Cross-sectional studies conducted on the Czech general adult (18+) population in 2017, 2019, and 2022
- Two-stage sampling individuals residing in randomly selected households were randomly chosen and asked for participation by a trained interviewer
- 2017 dataset: 3306 participants (RR = 60%), Self-I, M.I.N.I.
- 2019 dataset: 1077 participants (RR = 59%), RIBS, CAMI
- 2022 dataset: 3063 participants (RR = 59%), Self-I, RIBS, CAMI, M.I.N.I.
- All datasets representative of the Czech adult non-institutionalized population in terms of age, gender, level of education, and size of region of residence
- Descriptive statistics and regression models

# **Methods**

#### • CAMI

- Community Attitudes toward people with Mental Illness
- The shortened version contains 13 unfavorably and 14 favorably oriented items rated on a scale from 1 (strong agreement) to 5 (strong disagreement)
- We reversed positive items so that a higher score indicated less stigmatizing attitudes and a total score ranged from 27 to 135 points

#### • RIBS

- Respondents' past contact (i.e., reported behavior subscale of the RIBS) and their desire for future contact with (i.e., the intended behavior subscale of the RIBS) people with mental illness.
- Questions on living with, working with, having a neighbor, and continuing relationship with someone with mental health problems
- Intended behavior subscale are rated on a scale ranging from 1 ("strongly agree") to 5 ("strongly disagree"); value 3 to the "do not know" response option; total RIBS score ranged from 4 to 20, with lower values indicating a more positive direction

# **Methods**

#### • SELF-I

- 5 items:
  - Current issues I am facing could be the first signs of a mental illness
  - The thought of myself having a mental illness seems doubtful to me
  - I could be the type of person that is likely to have a mental illness
  - I see myself as a person that is mentally healthy and emotionally stable
  - I am mentally stable, I do not have a mental health problem
- Each item rated on a 5-point Likert scale with "1 = don't agree at all" and "5 = agree completely"
- Items 2, 4 and 5 inverted so the higher scores indicate higher self-identification with having a mental illness; range from 5-25
- M.I.N.I.
  - Mini International Neuropsychiatric Interview
  - Psycho-diagnostic instrument which has demonstrated a high concordance with clinicianassessed diagnosis of mental disorders

## **Results**

Regression model assessing the CAMI score in 2019 and 2022

CAMI score

			Estimate	SE	t- value	p-value	
	Intercept		36.89**	0.95	39.02	< .01	
<	Year (2022)		0.34	0.29	1.15	0.25	>
	Gender		1.91	0.27	7.18	< .01	
	Age		0.008	0.01	0.62	0.54	
	Size of place of residence		0.15	0.17	0.92	0.36	
	Education		0.85**	0.15	5.7	< .01	
	Income		-0.01	0.21	-0.7	0.94	
		Self- employed	-0.53	0.53	-1.01	0.31	
		Unemployed	-1.39	0.91	-1.53	0.13	
	Work	Student	-0.81	0.82	-0.99	0.32	
	status	Retired	0.2	0.5	0.4	0.7	
		Other	0.4	0.54	0.75	0.45	

Note: The referential year was 2019, gender category 'male' and work status 'employed'.

# **Results**

#### RIBS - reported behaviour items (1-4) in 2019 and 2022

RIBS reported behaviour item, n (%)	20	2019		022	<b>X</b> <sup>2</sup>	DF	p-value
	Yes	No	Yes	No			
Are you currently living with, or have you ever lived with someone with a mental health problem?	77 (7.1 %)	1000 (92.9 %)	327 (11.1 %)	2614 (88.8 %)	13.3	1	< .01
Are you currently working with, or have you ever worked with someone with a mental health problem?	99 (9.19 %)	978 (90.8 %)	472 (17.4 %)	2246 (82.6 %)	39.7	1	< .01
Do you currently have, or have you ever had a neighbour with a mental health problem?	138 (12.8 %)	939 (87.2 %)	433 (16.4 %)	2209 (83.6 %)	7.3	1	< .01
Do you currently have, or have you ever had a close friend with a mental health problem?	170 (15.8 %)	907 (84.2 %)	637 (22.2 %)	2226 (77.8 %)	19.7	1	< .01

Descriptive statistics of the RIBS intended behaviour composite score (items 5-8) and t-test comparing the score in 2019 and 2022, no covariates

	2019			2022				
	Ν	Mean	SD	N	Mean	SD	t-test	p-value
RIBS composite	1077	11.2	4.2	3063	12.1	3.7	-5.71	< .01
score								

#### Regression model assessing the RIBS composite score (items 5-8) in 2019 and 2022

			Estimate	SE	t-value	p-value
	Intercept		9.8**	0.51	19.3	< .01
<	Year (2022)		1.15**	0.15	7.62	< .01
	Gender		0.69**	0.14	4.98	< .01
	Age		-0.004	0.006	-0.55	0.58
	Size of place of residence		-0.08	0.09	-0.88	0.38
	Education		0.21**	0.07	2.84	<.01
	Income		0.16	0.11	1.5	0.13
		Self- employed	0.211	0.28	0.75	0.45
	Marchaster	Unemployed	-0.09	0.44	-0.2	0.84
	Work status	Student	0.4	0.43	0.92	0.36
		Retired	0.13	0.25	0.53	0.59
		Other	0.72**	0.27	2.71	< .01

### Results

Note: The referential year was 2019, gender category 'male' and work status 'employed'.

## **Results**

The density distribution of the SELF-I score in 2017 and 2022, of participants scoring positively for alcohol use disorder, anxiety, depression or suicide risk



# Discussion

- No significant change in attitudes as assessed by CAMI between 2019 and 2022
- Positive and significant changes in social distance in terms of both past and intended contact with PWLE as assessed by RIBS
- Positive and significant changes in self-identification with having a mental illness as assessed by SELF-I among those who screened positively for depression, anxiety or suicide risk as assessed by M.I.N.I.
  - No positive change among those screened positively for alcohol use disorder
- The role of a) national anti-stigma program, b) pandemic situation




# Initiatives to tackle the stigma challenge

#### Successful programmes to combat stigma





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53

Sign in

#### A global team working together to multiply our anti-stigma efforts

The Global Anti-Stigma Alliance is composed of 29 leaders and experts in the mental health field, representing 25 organizations across 14 countries, and our membership continues to grow.

GASA members are actively working to eliminate the stigma and discrimination associated with mental illness. Through sharing best practices and collaborating on the latest research, we can

#### WHAT'S NEW

#### Global Anti-Stigma Alliance (GASA) meeting in Prague, Czechia, November 10-11th, 2022



# on the level

### about mental health and illness

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## Stigma and its impact



- Self-stigma is defined as the way in which people with mental health conditions see themselves as being mentally unwell and, therefore, of lesser value
- Stigma by association refers to the internalisation of stigma by close associates of people living with mental health conditions (eg, family members)
- Public stigma (also referred to as interpersonal stigma) refers to the way in which people in a given community or society views and acts toward people with mental health conditions
- Structural stigma (also called systemic or organisational stigma) refers to discrimination in laws, policies, and in cultural and organisational practices



#### **Negative impacts**

- 1. Personal
- 2. Structural
- 3. Health care and social care impacts
- 4. Social and economic





# **Personal impacts**

# Personal impacts

#### Lived experience survey

 Participants reported experiences of discrimination in all aspects of their lives, from blatant discrimination in social interactions and at work, to social isolation and loneliness, shame and secrecy, and damaged marital prospects

#### Systematic review

- People with mental health conditions who perceived greater public stigma found their own condition more threatening than other respondents. They also reported more self-stigma, more hopelessness, poorer recovery, and reduced quality of life
- Among people who anticipated or experienced high levels of discrimination, psychological distress and shame were also increased, and empowerment and quality of life were reduced
- Self-stigma is positively associated with a why try effect, which leads people not even to attempt important activities (eg, applying for a job) because of the expectation of failure
- Loss of confidence can have negative effects on hope, quality of life, recovery, stigma resistance, and social functioning, and may increase suicidality



## Structural impact

# **Structural impacts**

#### • Systematic review

- Striking examples of discriminatory legislation exist in many countries, including prohibitions on marriage, violations against property rights, and prohibition from voting in elections
- Psychosocial interventions with proven effectiveness, are often not implemented
- Only qualitative and no quantitative papers on structural discrimination as a consequence of public stigma
- Several qualitative studies from different parts of the world described discriminatory laws or judicial practices arising from public stigma, for instance, using an unsubstantiated allegation of dangerousness against a PWLE in a court ruling. Two studies from African countries described public stigma as a barrier for PWLE to be involved in policy making. Three studies, two from Africa and one from Europe, reported participants' beliefs that public stigma led to inadequate funding and provision of health care. One English study described respondents' experience of going through the process of welfare benefit applications as stigmatizing



# Health care and social care

impact

# Health care and social care impact

#### • Systematic review

- Many cross-sectional and longitudinal studies identified in our review reported the impacts of stigma and discrimination on health-related outcomes, such as symptoms of depression, anxiety, post-traumatic stress disorder, psychosis, substance use conditions, suicidality, physical symptoms, disability, and recovery
- Prejudice by health-care staff has been linked with worsened health outcomes and physical health care because of diagnostic overshadowing, in which physical symptoms are misattributed to mental health conditions. These forms of health discrimination contribute to reduced life expectancy among people with mental health conditions
- Stigma is also associated with low investment in mental health care



# Social and

## economic impact

# Social and economic impact

#### • Systematic review

- Stigma limits a person's active participation in society with respect to education, employment, establishing healthy and safe social interactions, and starting a family
- Stigma affects the labelled individual but also, by association, family members and carers, for example by damaging the marital prospects of siblings, or when parents are blamed for their child's condition
- The anticipation of stigma, such as the fear of being discredited by police, having to withdraw from educational activities, or being avoided by family, friends, neighbours, also accounts for substantial negative effect
- People also report losing friends after disclosing a mental health condition
- High levels of stigma towards people with mental health conditions can lead to acts of neglect or abuse, such as shackling, verbal and physical humiliation or ridicule, sexual abuse, and violence, which has been reported from south Asia, Africa, North America, and Europe
- In employment settings, many people with mental health conditions decide not to disclose their condition due to fear of discrimination
- Housing conditions might be poor due to stigmatising attitudes of landlords who may refuse to have a tenant with a mental health condition

# Social and economic impact

#### • Lived experience survey

"The most difficult for me in the period as I was ill, was how the people at work treat me." Person in Spain

"Not being able to talk to any of my family members about what I was going through. Not knowing where to start. Moreover, opening up to a friend who in turn rubbished me saying that I am demon possessed and should go to church instead of a psychologist." Person in Botswana

"People see it like it is some form of weakness that comes from you. You are avoided like it is contagious. It is seen like it is not a serious problem and you can snap yourself out of it." Person in Nigeria



## Discussion



-

### **Stigma & negative consequences**

- Causation or mere association?
  To what extent does stigma lead to discrimination?
  - Does reducing stigma result in additional positive outcomes beyond simply decreasing stigma itself?



## Stigma & negative consequences

1. Discrimination 2. Self-care



# Experiences from national anti-stigma program

- Anti-stigma program is defined negatively defensive reactions
- Stigma as a concept not comprehensible to some groups, such as children
- Is mental health literacy a better framework in some cases?

#### Discussion

- We must go beyond merely encouraging populations to express better attitudes towards people with mental health problems, and focus of a more universal and human-rights oriented approach based on actionable supports in mental health
- We need actions in three areas: discrimination of people with mental health conditions; self-stigma of people with mental health conditions and their loved ones; population mental health literacy and resilience.



Time to reconsider our strategy?

## Anti-stigma vs. Mental health literacy



## Anti-stigma vs. Mental health literacy

Change in attitudes

- Knowledge and skill to obtain and maintain good MH
- Understanding mental illnesses and their treatment
- Positive attitudes
- Readiness to provide MH first aid and seek professional care



## What can you do?



Which negative consequence of stigma do you want to address? Understand the evidence base and pursue projects with high added value



## Advocate

- Use scientific evidence
- Work on all possible levels – service level, local, regional, national, international
- Communicate
- Collaborate with media





## Work with media

- Train journalists & disseminate media guides
- Establish long-term collaborations

## Engage people with lived experience...





## ....but provide them with a good training first.



### Become a role model







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