Stigma and stigmata

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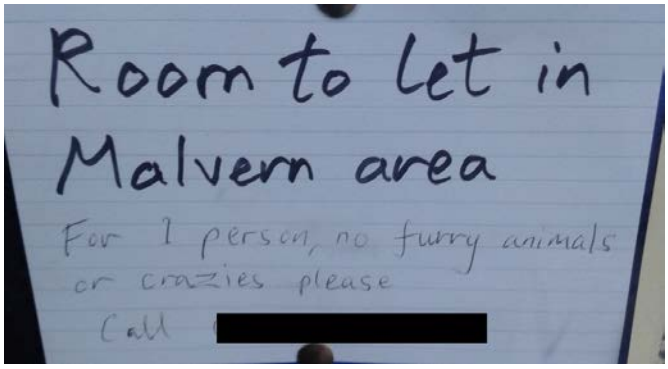
I am going to give a brief introduction to the field of stigma and spirituality, my aim here being to offer a basic conceptual framework.

I witnessed stigma and discrimination in action, in my home town in June 2015.



The word stigma is directly from the Greek. Originally, in the first century CE, stigma meant a mark, tattooing, scarring or burning, which identified to whom slaves or soldiers belonged. Stigma came to mean: 'An attribute that is deeply discrediting and reduces the bearer from a whole and usual person to a tainted, discounted one.'[1]
The word stigmata is also derived from the Greek- referring to the marks of crucifixion on Jesus' body.

Stigmatized individuals are labeled, set apart and rejected. They are associated with negative stereotypes and this leads to discrimination against them; hence they experience loss of status and reduced life opportunities.

Mental illness stigma has received a lot of press coverage since Prince Harry spoke out about his struggles following his mother's death,[2] and Prince William has advised that the traditional British Stiff Upper Lip is not always healthy[3].

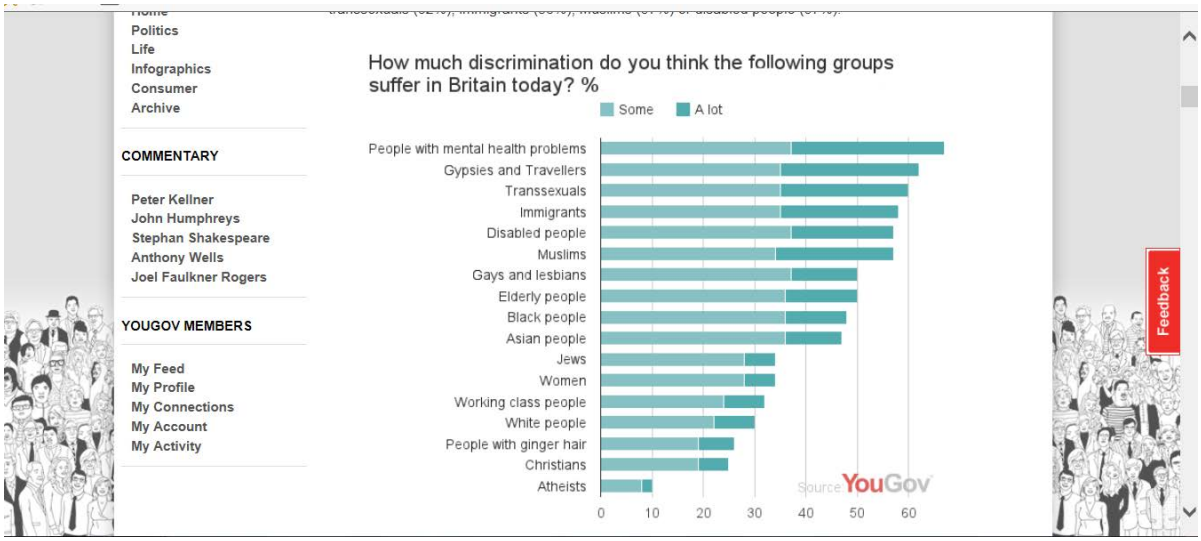
So that's it - job done, no more stigma anywhere, we can all go home... If only!

I was involved in the first college anti-stigma campaign 'Changing Minds: Every family in the land' in the early 2000's. Things have improved, but there is a long way to go before those who have experienced mental illness are not discriminated against and mental health care is given the same resources as physical health care.

Today we are thinking about stigma, religion and spirituality. There are healthy and unhealthy forms of religion. For most people most of the time religion is good for their mental health and many service users and experts by experience find spirituality supportive and want it to be acknowledged.

My argument is that we should support service users to identify healthy religiosity and what helps them to flourish, and help them recognize and address negative unhealthy spiritualties which are destructive.

People with mental health problems are acknowledged to suffer discrimination in modern Britain. A 2013 You Gov poll put people with Mental health problems as the most discriminated against in Britain today.



Of course mental illness isn't the only thing that is stigmatized. The same is true for those with visible disabilities, lesbian, gay bisexual and transgender (LGBT) people, deaf sign language users, people with epilepsy, HIV and sexually transmitted diseases.

Stigma is often associated with perceptions of threat, uncontrollability and dangerousness. At Halloween 2013, Tesco & Asda thought it appropriate to market a scary 'psycho ward' orange jumpsuit inmate's uniform as costume. They did respond to protests and the costumes were withdrawn.

Because of stigma, people don't tell others about certain conditions, so they are rarely discussed. This leads to ignorance and lack of knowledge in the community and to increasing fear, which stokes prejudice, a problem of attitude, and to active discrimination.

Discrimination against those with mental health problems lead to societal rejection, poorer healthcare treatment and health and economic disparities.

The lack of parity of esteem of mental and physical healthcare leads to poorer resourcing for mental health conditions.

Systemic impact UK

- Only 25% of people with mental illness get treated; 80% of diabetics
- People with mental illness die 15-20y early

- Mental Illness 28% disease burden;
- Mental Health treatment 13% NHS spend

Ultimately stigma and discrimination are behind the early death of so many with mental illness, 15-20 years earlier than people without mental health problems. [4]

This is a common problem worldwide. For example Major Depressive Disorder (MDD) is a severe illness with high morbidity and high rates of suicide. Looking at people who had experienced MDD for more than 12 months in 21 countries:

60% of the individuals diagnosed with MDD recognized that they needed treatment, but less than 1 in 5 were adequately treated in high income countries, going down to 1 in 27 treated in Low & Medium Income Countries. [5]

There are two main ways of looking at stigma; action orientated, and experiential.[6]

If we look at how stigma works through the action orientated lens, we can identify:

- *Structural discrimination*, which refers to discrimination through laws and policy: e.g. Mental Health funding
- *Public stigma*, which refers to the widely held negative stereotypes that lead through prejudicial attitudes to rejection and distancing oneself from those perceived to have mental illness.
- *Affiliate/courtesy stigma*, the way in which those who live with or work with the stigmatized group are also stigmatized to some degree. Affiliate stigma to some degree explains the poor attitudes held by some doctors towards psychiatrists [7]
- *Provider stigma*, the way that healthcare systems and staff discriminate against those with mental illness.
- *Internalized/self-stigma*, the acceptance of diminished opportunities because the individual accepts societies stigmatizing judgment, and feels people with their diagnosis can't achieve or don't deserve any better.

From the experiential viewpoint, stigma can be subdivided according to what is experienced into-

- *Perceived stigma*, what is considered to be most people's view of those with the stigmatizing condition
- *Endorsed stigma*, when people agree with stigma, prejudice and discrimination
- *Anticipated stigma*, where the service user expects rejection, which may of course change their behavior e.g. to hostility, leading to a self-fulfilling prophecy
- *Received stigma*, when the service user experiences discrimination, is rejected or devalued
- *Enacted stigma,* another term that refers to actual discrimination in practice.

Stigma impact.

- Hopelessness “Why Try?”
- Low self esteem
- Stigma Stress
- Late diagnosis Physical & Mental
  – Worse outcomes
- Limited lives
- Suicide?

Anticipated stigma inhibits the chance the individual will present for early diagnosis, leading to worse long term results.

Experienced stigma and discrimination leads to hopelessness, the individual feels ‘Why Try? They experience stress and low self-esteem.
Provider stigma and structural discrimination are another factor leading to late diagnosis and poor treatment of both physical & mental health problems in the stigmatized group, leading to worse treatment outcomes, and more interactions with the criminal justice system. The resulting victimization, social isolation, unemployment, poverty and homelessness lead to very limited lives for some long term mental health service users, and these are factors known to increase the risk of suicide.

Case History

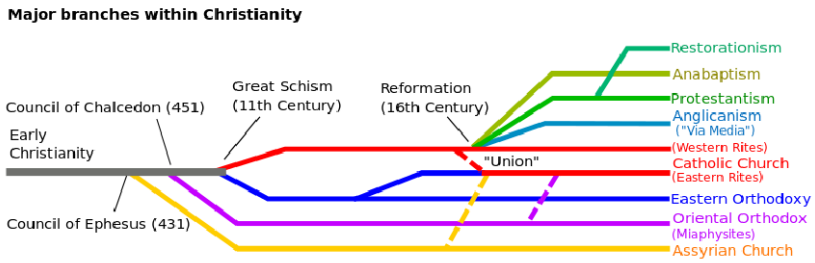
Ruth was working long hours and overnight shifts away from home without her usual supports. Following her fathers’ sudden and unexpected death, and a run of sleepless nights, she became manic and was eventually detained on a section. Ruth recovered sufficiently to return to work, but soon became depressed and suicidal, resulting in another detention. She was told that due to the severity of her illness she would probably never hold down a job or have a long term relationship. Lonely, isolated and unable to work she moved back to live with her mother and began to come to church.

Over several years, with medication and learning, by recognizing early warning signs and psychological therapies from the mental health services, and with a loving supportive community through the church, Ruth’s mental health became more stable. She began to rebuild her life and relationships and came to a living and active faith. Ruth was able to take on small tasks and roles within church which started a positive feedback loop.

Ten years ago she got married, and now has two children, one of whom was born premature. Ruth coped with these changes and challenges without becoming ill. The children are now at school and Ruth has a part time office job and a full active social life, and helps others through the church. She has been off all psychiatric medication for 15 years. She credits the church community with getting her through her mental illness.

One of the challenges in thinking about Stigma and spirituality or religion, is being specific about the type of spirituality.
You can’t simply say ‘Christians think’...Christianity for example, has multiple denominations.

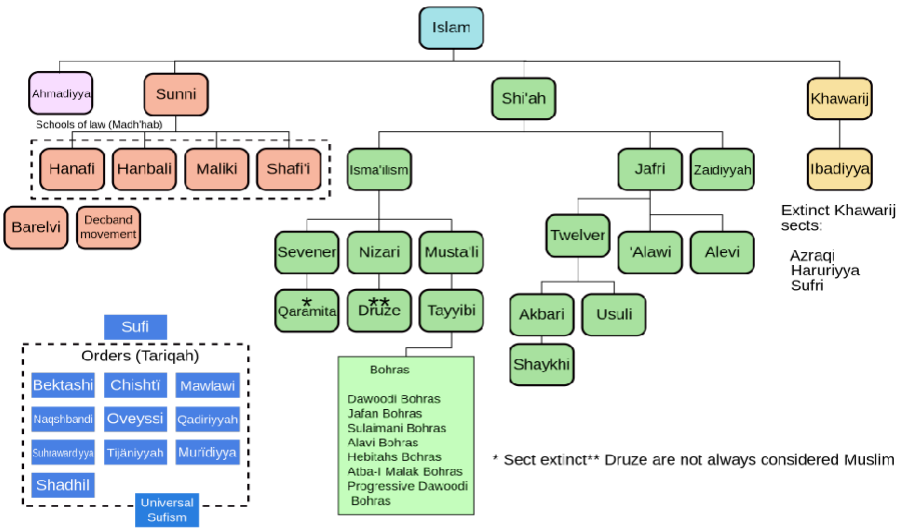
“Christians think…”



There are variations between the different branches of the Christian family, not in the overall teaching but in the emphasis placed on different aspects. Some Christians, mostly from Pentecostal and Charismatic churches, teach that if you confess your sins, pray hard enough and really mean it then God will ALWAYS heal you. A Charismatic church community full of forty-year olds can get away with this theology for a few years, but as people age and die this challenges this theology. Some Christian groups believe that mental illnesses (along with addictions, homosexuality and several other phenomena) are caused by demon possession and will seek to cast out these demons.

In the Church of England and Roman Catholic churches each diocese has trained ‘deliverance ministers’ (new term for exorcists) and psychiatrists to advise on cases, and exorcisms are very rare. Similarly for Muslims there are a variety of attitudes towards mental illness largely driven by local culture and interpretations of Islam

“Muslims think….”



I recently spoke at a Muslim students' conference and many of the issues were exactly the same as faced by committed Christians:

> 'How can you be a committed, spiritual believer and still struggle with mental illness?'
> 'If you pray you shouldn't need to take medications too.'
> 'Real Muslims don't get depressed.'

Some Muslims think that mental illness can be caused by the presence of Djinn (spiritual beings, which are not human and not angels). Evil Djinn can take over a body, and can be driven out by prayer, fasting, rituals and beating, and it is permissible to beat the person severely because you are really only beating the Djinn!

Perceived Causes of MI

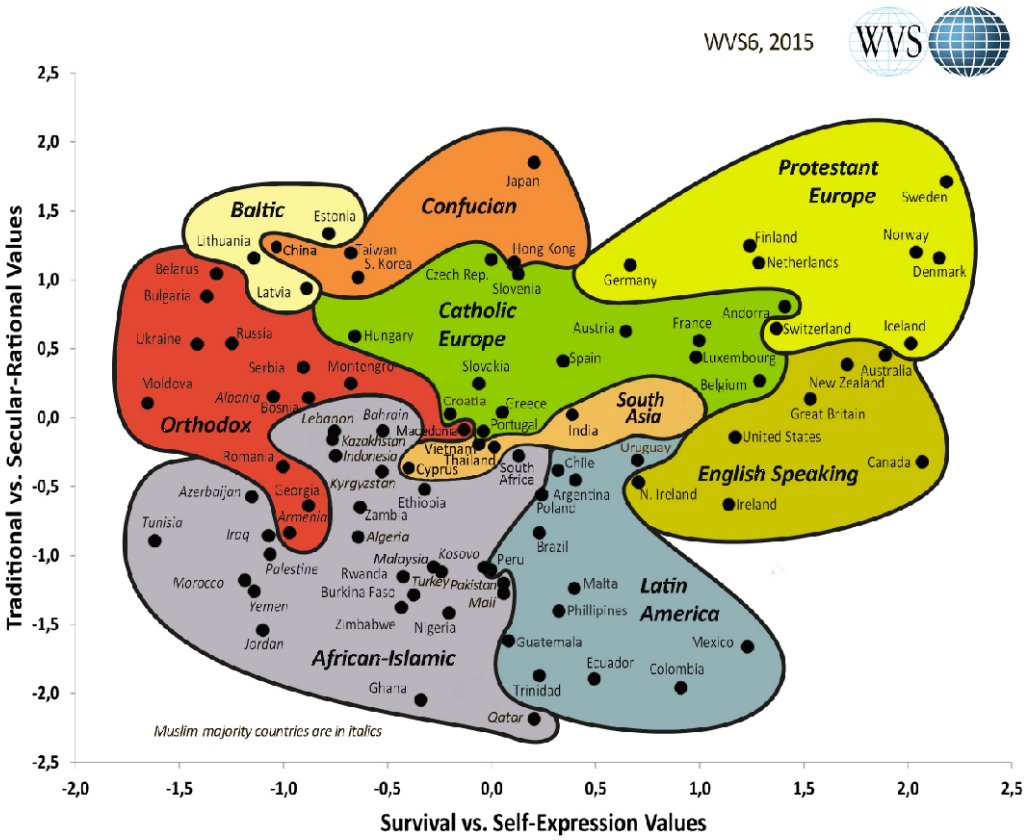
Spirit Possession: Christians, Muslims
Witchcraft & punishment: Zambia, Pakistan
Neglect of traditional rituals: Uganda
Weakness, laziness: Hispanic, Japan
Loss of Dusha: Russia
Neglect of Dharma: Bangalore
Bad Karma: India, China

For many service users, their religion helps them to cope with their mental health problems, through prayer and scripture reading, through individual pastoral support and through an accepting and supportive community, which gives them a valued social role. I think here of the young man with learning disabilities at my church who always collects the hymn books with a smile, and stacks them carefully. He enjoys doing this job, which earns him praise and gives him a role in the community. The severity of stigma in a particular community is largely determined by the perceived cause of mental illness.

If the cause is seen to be internal, irreversible and your own fault (e.g. laziness, weakness) there is more stigma than if the cause is seen as external and reversible (e.g. witchcraft). Stigma theorists initially thought that teaching about the biological and genetic causes of mental illness would lead to less discrimination, since a person can't be blamed for their biology. However this seems not to be the case since the irreversible nature of a genetic condition makes it more highly stigmatized.

We know that people with schizophrenia have better social outcomes in less industrialized countries and worse in highly capitalist and individualistic countries.[8,9] It has been suggested that this is due to less stigma and discrimination in the developing countries. If we combine two sets of data we can see that this is unlikely to be the answer.

If we take the Inglehart–Welzel Cultural Map from the World Values Survey (WVS, 2000):



This shows the world's countries separated on an axis of more or less traditional (i.e. religious) vs. secular. At one extreme, 98% of those interviewed in Indonesia affirm that 'Religion is very important to me' at the other end just 3% say this in China.[10] Traditional values emphasize nationalism and religious conformism. People are generally obedient to authority and have a high regard for marriage. Secular-rational values emphasize the opposite of these points.

The other axis is survival vs self-expression values, which is closely linked to the economic status of individuals in those countries.

High scores on survival values predict that security is prioritized over individual liberties: outsiders are viewed with suspicion, few people are politically active, homosexuality is seen as unacceptable, and there is a weak sense of happiness. Self-expression values are the opposite. As countries develop and survival is more secure most travel diagonally towards top right. War brings uncertainty and risk of death, and so tends to push a country down and left.

The Stigma in Global Context- Mental Health Study is a vignette and questionnaire survey of stigma in 16 countries. [11] The results are plotted to show levels of stigma in each country.

Stigma in Global Context- Mental Health Study

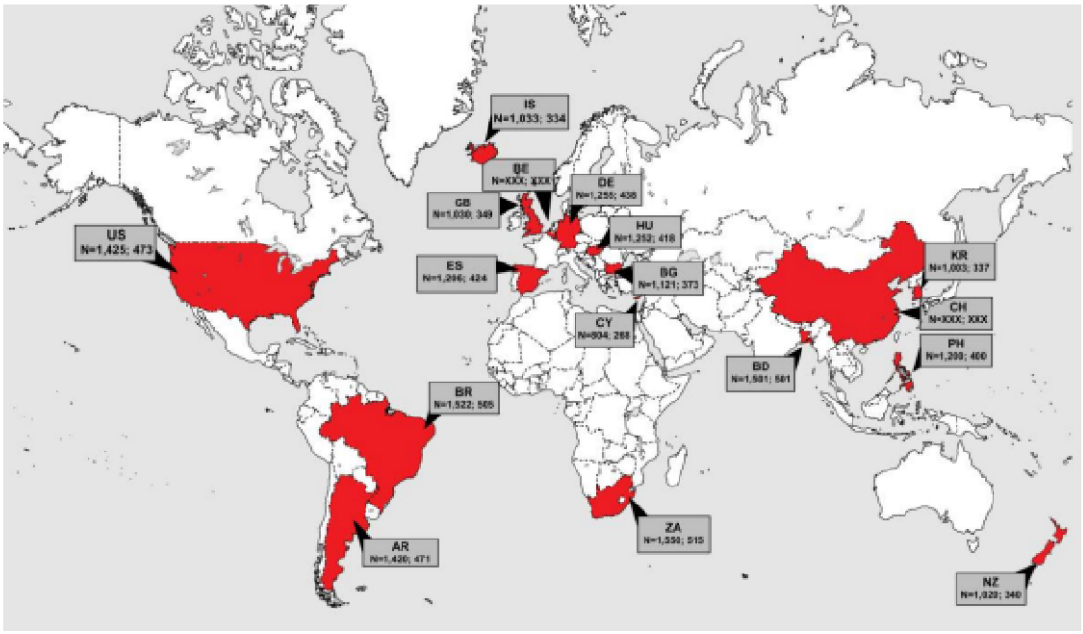


FIG. 1.—Global levels of public stigma. Countries and sample sizes (both total and effective N) for schizophrenia vignette, SGC-MHS. AR = Argentina, BD = Bangladesh, BE = Belgium, BG = Bulgaria, BR = Brazil, CH = China, CY = Cyprus, DE = Germany, ES = Spain, GB = Great Britain, HU = Hungary, IS = Iceland, KR = Korea, NZ = New Zealand, PH = Philippines, US = United States, ZA = South Africa.

What Matters Most.

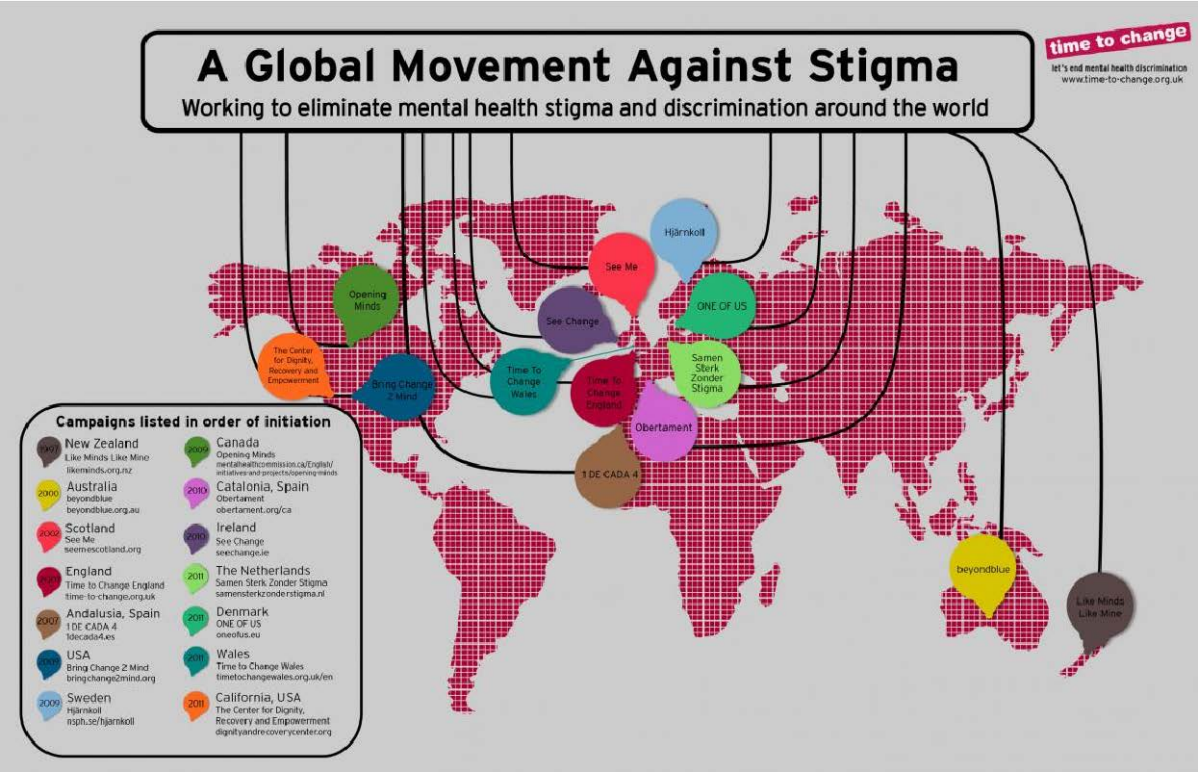
- Perpetuating lineage: China
- Save face: China/ Albania/Philipines
- Show no weakness: American Samoa/ Latino's
- Be economically productive: Germany
- Make a good marriage: Pakistan/ Jewish
- Look after community: Ghana

The intensity of discrimination against those with mental health difficulties is also related to 'What matters most' in that particular cultural group.[12]

For those of Chinese descent continuing the family line is of major importance and those who cannot establish healthy relationships and have children or who bring shame on the family are greatly discriminated against. In Ghana the valued role is supporting the community in practical ways and those who always need support are stigmatized. In the West, e.g. Germany, it is being economically productive that is most valued, and those who don't have a job outside of the home are discriminated against.

How can we counter the effects of stigma and discrimination?

There are three main tactics: *Contact, Education and Protest.* The Time to Change campaign covers each of these areas and offers many resources for personal and local action.[13]



Contact means ensuring that those with mental illness come into contact with those who haven't yet got a diagnosis, either directly or indirectly through positive media coverage of mental health and recovery. Education is both providing facts about mental illness and also about the rights of those with mental illness. Protest includes emailing media outlets and shops that discriminate, as well as challenging those around us with use of language and more formal campaigns e.g. Time to Change.

Jewish Association for the Mentally Ill

There are online resources around Religion and Mental Health to which we can point our patients.
Jewish association for Mental Illness advocates and provides services for Jewish people with mental health problems. [14]

Different Christian churches have different projects.[15] 'The mental health' project is Roman Catholic, 'Mind and Soul' is Free Church, and 'Mental Health Matters' is Anglican.

There are resources being developed for the Muslims community and mental health[16].

Stigma has come full circle with the reclaiming of tattooing and marking by those who have personal experience of mental illness. Project Semicolon [17]was started by Amy Bleuel who was an active member of her local church, motivated and sustained by her faith, in 2013, in response to her father's suicide. People who have attempted or been close to suicide get a semi colon tattoo to show that they are happy to talk about mental illness.

Project Semicolon

About Project Semicolon, Amy Bleuel explains:
'In literature, an author uses a semicolon to not end a sentence but to continue on. We see it as you are the author and your life is the sentence. You're choosing to keep going.... Despite the wounds of a dark past, I was able to rise from the ashes, proving that the best is yet to come. When my life was filled with the pain of rejection, bullying, suicide, self-injury, addiction, abuse and even rape, I kept on fighting. I didn't have a lot of people in my corner, but the ones I did have kept me going. In my 20 years of personally struggling with mental health, I experienced many stigmas associated with it. Through the pain came inspiration and a deeper love for others. God wants us to love one another despite the label we wear. I do pray my story inspires others. Please remember there is hope for a better tomorrow.'

But all anti-stigma effort is complex and difficult, and we know mental illness is a killer. Amy, who inspired so many to keep going, died by suicide age 31years in March 2017, while I was preparing this presentation.[18,19]

We know what works to reduce stigma and we can all be involved - *Contact, Education, Protest*. Contact requires initially self-acceptance, and then for individuals to become visible by 'coming out' to friends, family, colleagues and faith communities as someone who has used mental health services. If we haven't used services ourselves, we can support our friends and family who have done so, to acknowledge this as appropriate for them. As psychiatrists, we can undertake education about mental illness, particularly for police, healthcare workers, teachers, religious leaders as well as the general public.
We can all check our own attitudes, and speak up when we hear someone stigmatising those with mental illness. We can support each other to watch the media, complaining against stigmatising portrayals and giving compliments where mental illness is well handled.

Cancer was once heavily stigmatised and now people speak much more freely about it. One of the changes is that many forms of cancer are now treatable so that people recover. Similarly, we need to support political campaigns for better funding for mental illness research, care and treatment, and support early intervention to improve the illness course for those affected in order to bring mental health to parity of esteem with physical health.[20]

As the Royal College's first anti-stigma campaign said: Mental Illness affects every family in the land, and we can all join Time to Change,[21] and act locally, nationally and globally to challenge stigma and discrimination wherever we see it.

proud to support
time to change
let's end mental health discrimination

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