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The Centre for Applied Research and Evaluation-International Foundation

Global Position Statement:

STIGMA, MENTAL ILLNESS AND DIVERSITY

Introduction:

Careif is an international mental health charity that works towards protecting and promoting mental health, wellbeing, resilience and resourcefulness with a special focus to eliminate inequalities and strengthen social justice. Our principles include working creatively with humility, dignity and balanced partnerships in order to ensure that all cultures and societies play their part in our mission of protecting and promoting mental health and wellbeing. We do this by respecting the traditions of all world societies, whilst believing that culture and traditions can evolve for even greater benefit to individuals and society.

Globalisation has created culturally rich and diverse societies. During the past several decades, there has been a steadily increasing recognition of the importance of societal and cultural influences on life and health. Societies are becoming multi-ethnic and poly-cultural in nature worldwide, where different groups enrich each others' lives with their unique culture.

Cultural transition and acculturation is often discussed as relevant to migrants and describing the need to integrate, when in fact it is of relevance to all cultures in an ever-interconnecting world. It is indeed necessary to be equipped with knowledge about cultures and their influence on mental health and illness. Culturally informed mental health care is rapidly moving from an attitudinal orientation to an evidence-based approach, therefore understanding culture and mental health care becomes greater than a health care issue.

This position statement builds on our previous Global Position Statement on Stigma (Careif Stigma 2015).

share knowledge change lives

The Evidence:

Over the millennia, humans have struggled to understand mental illness. Despite scientific advances which allow us to identify areas of the brain responsible for many processes, we remain perplexed by the diversity and subjectivity of such experiences and conditions. Industrialised societies have become materially sophisticated, but there is still extensive stigma attached to human diversity, including mental health diversity, despite this diversity being part of our natural way of being.

Humans have evolved from simple to complex biological beings, living in increasingly large and diverse societies. As this human complexity grows, so, inevitably, does the diversity of individual experience within these groups. Nevertheless, for a social group to survive and minimise chaos, agreed rules and regulations are necessary. These reflect the values and beliefs of the larger group and change over time. Those who reject or rebel against the norm, or are unable to respond effectively to the accepted norm will be stigmatised and either marginalised, persecuted or forced into acceptance. Fear, isolation and anxiety underpin these processes.

The concept of stigma can be traced back to Ancient Greece when a person who had contravened the rules was physically marked out from the rest. Today, stigmatisation may be more subtle, but it retains the same negative association as in the past. One indicator of stigma is the language used to describe the person who deviates from the social norm. Terms used to describe those who deviate are usually pejorative and some have become politically unacceptable (Yoganathan, N. 2015). Some evidence from recent empirical studies regarding feelings and experiences as a result of the stigma of mental illness is strikingly similar to evidence from similar studies conducted a decade ago (Howe et al., 2014; Dinos et al., 2004).

Can we really dispel the stigma of mental illness without dispelling a number of other stigmas as well? How can we reduce feelings and experiences of stigma associated with mental illness on the one hand if there is stigma experienced by possessing another stigmatised identity, e.g. gender or race related, on the other hand? There have not been any high profile anti-stigma campaigns that have attempted to capture the complexity of different stigma interactions and therefore different stigmas have been targeted in isolation. One could possibly wish that, if all different anti-stigma campaigns worked effectively, then different stigmas would be tackled simultaneously (albeit in silos). This has not been the case so far. It may be beneficial for some media anti-stigma campaigns to start sharing with the public some of the information that has only been shared so far amongst academics and health professionals; such as that lesbian, gay, bisexual, and transgender (LGBT) and black and other minority (BME) groups (as well as other stigmatised groups), are significantly more likely to have mental health problems including suicidal thoughts. One could argue that such campaigns would dilute the simple messages that a straightforward anti-stigma campaign can deliver. Nevertheless, campaigns to tackle social exclusion should also have the aim to educate the general public about the impact of stigma on someone's life. Similarly, campaigns to dispel the stigma of mental illness could incorporate messages about what creates mental ill health (e.g. social exclusion and discrimination) as opposed to taking mental illness as a given or a starting point and working from there (Dinos, 2014).

What has this got to do with health or mental illness?

Physical and mental health/ill health and stigma.

I'd like to see a world where 'mental health' isn't separated into a condition that only affects a part of the population; we all have an ongoing mental health status throughout our lives and it needs to be nourished, protected and respected at all times. (Careif/WPA Wellbeing, 2016)

Two words are commonly used to describe the absence or impairment of health: 'illness' and 'disease'. Although the two terms are often used synonymously, when it comes to the mind, we generally refer to mental illness, not disease. This implies that the word 'disease' is used for something that can be objectively measured and proven, whereas illness is something subjectively experienced.

Medical practice has evolved through defining and scientifically measuring abnormalities that are detrimental to health. We now recognise and accept that health is not only physical but also influenced by social and psychological (including spiritual) conditions. Definition is easier when experiences are physical (bodily): physical conditions can be defined through statistical norms. When experiences are primarily of a mental kind (e.g. emotions, perceptions, thoughts and beliefs) their subjectivity makes it difficult not only for others to understand and accept but also sometimes for the individual (patient) themselves to explain their experiences. Psychological and spiritual experiences have no objective benchmarks, they are defined by social constructs determined by the values of society. These may be prone to fluctuation over time, but if the underlying values remain rigidly held, anyone or anything deviating from them, will be stigmatised. This results in the use of terms to describe mental illnesses, which are usually discriminatory and offensive e.g. 'nutter' 'basket case' 'loony'.

"I am a journalist and artist with a history of paranoid schizophrenia. I see a lot of stigmatising language in the British press and, as such, have written a poem to reflect this".

'Do not read the newspapers and be fearful'

Do not read the newspapers and be fearful;
I am not violent. I am actually cheerful.
I am a human like you with kindness and compassion.
I am real, strong and for art I have a passion.
I am the sunlight in the sky, and the dust in the moon.
I am anything but a nutter, crazy or a loon.
When you read the stories in The Sun,
I am so sad of what's to come;
As I see the fear in your eyes;
That you my friend may wish to sever ties.
Do not read the newspapers and be fearful;
The terror they create makes me so tearful.

An adaptation of a Mary E. Frye poem by Erica Crompton. (UK)

Over the years, various medical conditions have been stigmatised due to fear, lack of understanding and/or social judgements e.g. bubonic plague, tuberculosis, cancer, sexually transmitted diseases and, more recently, AIDS. Stigma has reduced as we have gained better understanding and developed better treatments, but still some people find it difficult to confront their inherent fear and use euphemisms e.g. the 'C word' for cancer.

Most mental disorders, though, notwithstanding advancements in our understanding and treatment, remain a source of fear and uncertainty because they elude biological objectivity. This is despite increased categorisation of mental illnesses e.g. World Health Organisation, International Statistical Classification of Diseases and Related Health Problems (ICD10) and The Diagnostic and Statistical Manual of Mental Disorders (DSM) based on descriptions and consensus rather than objective, biological evidence, hence remain ambiguous. Table 1 tracks this expansion in categories of mental illness (Willis, J., 2015).

Date	Organisation	Categories / Conditions
1840	American census	Idiocy / insanity
1870	Association of Medical Superintendents of the American Institutions for the Insane (1844)	Dementia / dipsomania / epilepsy / mania / melancholia / monomania / paresis
1917	Statistical Manual for the use of Institutions for the Insane	22 categories
1952	Diagnostic and Statistical Manual of Mental Disorders DSM-1	106 conditions
1968	DSM-2	182 conditions Removal of homosexuality as disorder, 1974
1980	DSM-3	265 conditions
1994	DSM-4	297 conditions
2013	DSM-5	3 major components: the diagnostic classification, the diagnostic criteria sets, and the descriptive text

Stigma self-harm and suicide.

Stigma can embrace both negative and prejudicial attitudes and also discriminating behaviour towards people with mental health problems, including mental illness, suicidal behaviour and self-harm. Such stigma could be considered as a life-limiting condition as the secrecy and shame it propagates prevents people from disclosing and professionals from asking, especially around suicide and self-harm (Reynders et al., 2014). In particular self-stigma is hugely painful, and stigmatising language about suicide and self-harm from professionals which may have connotations of illegality and therefore shamefulness will exacerbate this (Maple et al., 2010).

Evidence suggests that stigma and self-stigma continue to be a barrier to effective help-seeking particularly in men experiencing suicidal thoughts. Healthcare professionals who are empathetic and compassionate encourage increased disclosure by patients about their concerns, symptoms and behaviour, and are ultimately more effective at delivering care (Larson, 2005). Due to stigma, shame, fear or embarrassment people may conceal or minimise their symptoms of mental illness, self-harm or suicidal thoughts (Cole-King A. et al, 2017).

Stigma, diversity and choice.

Culturally sanctioned behaviour will give you less stress and thus be good wellbeing in terms of mental health (Careif/WPA Wellbeing, 2016)

Survival of the human species requires food, shelter and procreation. Developed societies may offer us choices e.g. whether to be a vegetarian or meat eater, drink or abstain from alcohol, follow a religion or be an atheist. If our individual choice is discordant with the idealised values, culture or religion of our society, we risk rejection and stigmatisation. Intolerance is based on narcissistic ideals, but are these purely narcissistic or do they reveal fear of diversity and the challenge this brings to the status quo? Choice of alternative diet may be tolerated, but choices that are perceived to threaten the established norm will be stigmatised.

Sexual diversity is more complex though: some may perceive this as a choice, but others would argue that it is part of human experiences. Nevertheless, stigmatisation will be manifest once more in the use of offensive terms e.g. 'bent', 'swings both ways'.

I'm lesbian, and when I was a teenager in the 1980s being gay was definitely frowned upon (worsened by the advent of AIDS). Wider society dictated that I was not 'natural' and that any relationship I might have was 'pretend', which undermined my own sense of worth and value (Careif/WPA Wellbeing, 2016)

Sexual diversity is a good example of how social values may change over time. Homosexuality was decriminalised in England and Wales in 1967 (in Scotland in 1980, and Northern Ireland, 1982), but it was only in 1992 that ICD declassified it from being a mental illness. Today, in some parts of the world, homosexuality is punishable by a prison sentence (including lashes) and even death or both. Alarmingly, homosexuality is seen by some, including in parts of the "developed world," as a treatable psychiatric condition.

Similarly, race and ethnicity, which are not a personal choice, are susceptible to stigmatisation and verbal abuse through the use of stereotypical terms such as 'Blacks' or 'Pakis'. Mental illness, too, is not

something people choose to have, yet it is sometimes viewed as self-induced. This results in anger, suspicion, blame, shame and guilt on the part of the individual and is reinforced by societal stigma. This may lead to poor adherence to treatment and impaired recovery. There are many stigmatising identities and group memberships that many of us belong to or will belong to at some point in our lives such as race, ethnicity, sexuality, physical illness, poverty, substance misuse, age, gender and so on. There is plenty of evidence to show that many groups of people who are at greater risk of stigmatisation because of their group membership, are also at risk of developing mental health problems because of this group membership (Bhui.K, & Dinov,S., 2011).

*I am a woman – I struggle to be recognised at times in a male dominated-world
(Careif/WPA Wellbeing, 2016)*

Stigma and the shame associated with it, whether based on gender, ethnicity religion or mental or physical illness or disability, cannot be separated from politics, economics and power relationships within society. The current globalised economic system, with all its benefits, is also contributing to rising financial and social inequality. Human society is also facing unprecedented threats and anxieties in the shape of climate change, global terrorism and technological warfare. In this context prejudice against and stigmatising of groups of people within society can be understood as an unconscious psychological mechanism employed by dominant groups to transfer experiences of anxiety, vulnerability, inadequacy and shame onto others.

This mechanism of splitting and projection can also be understood as a way in which a group or a society psychologically expels the guilt associated with limiting others' opportunities and treating them differently or inhumanely. If individuals or groups are seen as "less than", be it through manifestations of mental illness, perceptions of sexual deviancy and immorality, impurity (e.g. women's bodies, skin colour) and irrationality, they are essentially dehumanised and can be seen to deserve the treatment they receive. Physical and psychological oppression, silencing, marginalisation and invalidating of experience can all be justified in these terms. Any economic and political system which protects the powerful in society is invested in the separation and individuation of people, reinforcing the conviction that self-interest matters above all else and blocks from view the systemic determination of choices and outcomes (Wallace S., Nazroo J., Becares L., 2016). This places the responsibility for failure on the shoulders of those with the least power and social capital within society.

The psychological effects of experiencing stigma and the traumatic events which can surround this, whether it is based on gender, ethnicity, being a member of a stigmatised social group or mental or physical disability can have cascading effects down through generations. Intergenerational transmission of trauma can be a major cause of the manifestations of anxiety, depression and other psychological symptoms in young people (Bhui K., 2016). Unprocessed trauma within societies and within families can cause dysfunctional relationships. Domestic violence and marital breakdown can be higher in marginalised immigrant populations (Erez, et al., 2009) with traumatic consequences for future generations. Taking a three-generational history from young people who are suffering mental ill health as they approach adulthood can be revealing of social marginalisation or traumatic events in previous generations, particularly where immigration is a feature. Immigration always signifies a period of disorientation, loss and readjustment, and if unprocessed can lead to disturbance in individuals and

families. This is doubly reinforced when it has been precipitated by genocide, war, occupation or political oppression (Yehuda, Rachel et al., 2015).

Stigma and language

Language is an important element in either worsening or confronting and dealing with stigma. Euphemism and politically correct terms such as using 'mental health' when we actually mean 'mental illness' is intended to reduce the stigma but, sadly, has the paradoxical effect of worsening it. Even respected broadcasters frequently refer to 'mental health illness' when they mean 'mental illness'. This again is a reflection of unconscious anxiety and fear on the part of the larger group/society.

Another paradox lies in the use of diagnostic labels and definitions. These are essential for scientific understanding and research in the field of medicine, and we would not be where we are today without their validity. However, when we define we also confine and categorise, which may inevitably contribute to further stigmatisation of both those confined by the label and those excluded from it. A further paradox is that, however ambiguous the label may be, it can be containing and reassuring for all parties concerned in treatment, planning and management of mental health care.

The Dialectic of Stigma (the stigmatiser and the stigmatised)

*The way I am treated in my family and socially with respect has an impact [on my wellbeing]
(Careif/WPA Wellbeing, 2016)*

Stigma is usually perceived as a didactic, one-way process, the marker marking out the stigmatised. Not surprisingly, this has resulted in anti-stigma campaigns, in the UK, having only limited success, especially in addressing stigma relating to mental illness.

The recent mantra of Western clinical work is 'evidence-based practice'. This may be justified for expensive medical treatments and for conditions which can be objectively measured, but in psychiatry it has led to cognitive behavioural therapy (CBT) being used as a panacea. Whilst CBT is an effective and scientifically accepted treatment for certain conditions, it can also inadvertently trivialise serious mental illnesses and profound human experiences (symptoms) which defy rational explanation. This is another example of how we may unintentionally contribute to stigma.

Careif's approach is to address stigma from a dialectical perspective which recognises the duality of the process of stigmatisation. A truly holistic approach includes the needs of both the stigmatiser and the stigmatised. So, for instance, the contexts of mental ill health and human sexual diversity, training and research must be qualitative as well as quantitative, reflecting experience at a personal as well as collective level.

When human beings are cruel to each other for either religious, cultural or because of some form of psychopathology, I get disappointed and frustrated. I sometimes despair when I observe poor child care practices that seem to ignore the value of human individuality and reflect poor and damaging child-adult relationships (Careif/WPA Wellbeing, 2016)

A dialectic process implies dialogue between multiple agencies: government, religious and community leaders, teachers, health care professionals, patients and carers. Because beliefs and values are formed

during our early years, we propose that health education should be mandatory and should include unambiguous approaches to mental ill health and human sexual diversity.

Careif also acknowledges that changes to certain beliefs and values may take time (decades or even centuries) to achieve at a societal level. Hence it is important that we address stigma processes at an individual and small group level so that those who are stigmatised empower themselves and thereby free themselves from the process. Such personal and group freedom is essential to the current focus on recovery. In so doing, we must remain cognisant of the fact that we cannot force people into our 'box', thus reducing the probability of us becoming abusive. We must also be careful of the language we use both academically and in regular speech, including avoiding professional jargon as much as possible.

Stigma can also be self-inflicted (Kawika, Allen, Kim, Smith, Hafoka, 2016). Indeed, individuals often internalise the health belief systems of their culture as well as that of the wider society. Thus, not only do they need to confront stigma from the general society, but they must contend with their own cultural norms which may not be supportive of mental health difficulties, as well as their personal internalisation of shame. The challenge is to move all actors (society, cultural collective and individual) towards a position of acceptance. We must, however, acknowledge that for the cultural collective and the individual, the movement towards acceptance may be easier said than done, especially if the stigmatised hail from ethnic and racial minorities, as in addition to the stressors associated with mental illness, they face the micro and macro aggressions associated with racism and discrimination which can be very anxiety-provoking.

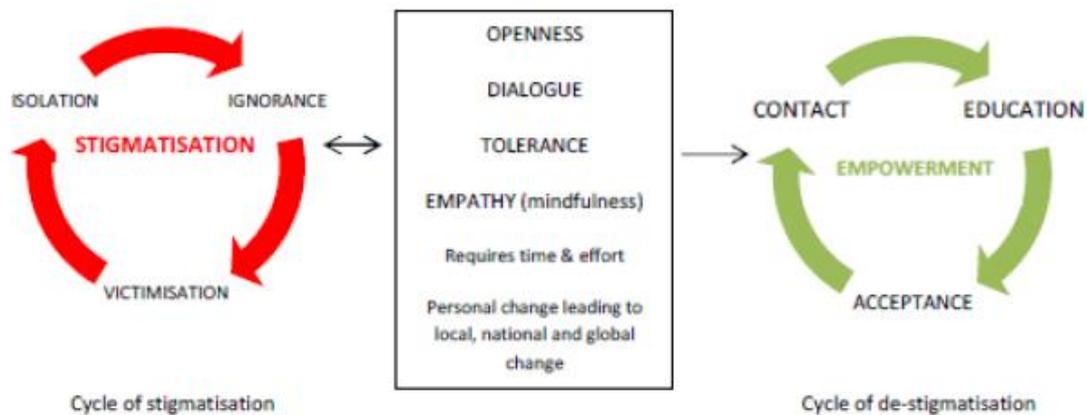
It is known that dealing with the societal stigmas and aggressions related to ethnicity and mental illness contribute to anxiety (Hopkins & Shook, 2017) and even though ethnicity may act as a buffer against the negative consequences of anxiety, the stigma associated with mental illness may be a negative factor in the decision to seek aid. Therefore, therapists who do not take into consideration the fears and emotional turmoil brought about by the everyday, almost constant, barrage of indignities wrought by racism and discrimination, are not addressing the problem in its entirety

Careif, through its advocates, will continue to inform and teach the public. For example, it is quite possible for individuals to demonstrate empathy towards those undergoing mental health difficulties and still engage in stigmatising behaviours. It has also been found that there is a perception that those with mental illness are of lower socioeconomic status, inferior and suffering societal restrictions (Tzouvara & Papadopoulos, 2014), moreover, since the degree and type of stigma varies by culture, it is important to tailor the message to the norms and realities of the recipients in order to make it relevant and thus, have a higher probability of being accepted (Dinos, 2015). This is, in fact, one reason we teach students the importance of incorporating viewing illness and recovery from a cultural perspective and to determine whether what is being observed is dysnormative or dysfunctional or any combination of these concepts (Lashley, Hassan, Maitre, 2014).

Careif will use its influence to bring attention to the relationship between citizens with mental health challenges and law enforcement personnel as police are usually the first to respond to incidents and disturbances in which the mental health of the individual is a factor. Unfortunately, the lack of training in, and comprehension of, mental health problems often results in mentally ill people being among

those who are viewed more harshly; presented with more citations; and stigmatised more than others (Schulenberg.2016) all of which have the propensity to lead to the criminalisation of these individuals.

The figure below reminds us of the process required. From stigma to empowerment
(Yoganathan, N. *Careif Stigma*, 2015).



Careif call for action:

Poor choice of words can perpetuate stigma, constrain thinking and reduce help-seeking behaviour. Stigma kills and Careif calls upon people in all sectors to play their part in tackling and eradicating the stigma surrounding mental illness and diversity. In addition to those already experiencing mental health problems, Careif suggests we must prioritise activities targeted at those most at risk, such as minority groups like LGBT and BME people who experience additional forms of inequality and discrimination.

Professionals/care providers: Patients expect the highest levels of professional standards of psychiatric care, regardless of who is treating them. Professionals must be aware of the high levels of responsibility and trust placed on them by patients, their carers and families and others. Professional bodies and service providers must develop strategies and plans to reach more vulnerable groups through better training of health professionals and other staff across all specialities and disciplines. In this context, there is great opportunity for professional groups to work collaboratively in addressing stigma, and to recognise the importance of including the wide range of other people and organisations who can have an equal contribution to make in supporting people living with mental illness and their carers.

Community Development: non-governmental organisations (NGOs), voluntary sectors, other community groups and individuals, working locally and in the international arena should work with people with lived experiences, to support staff to understand the needs and capacities of people from ethnic minorities, lesbians, gays, and bisexuals, groups with mental health problem and people with disabilities and set up new mental health specific programmes, and measure the impact of their programmes on mental health. They should facilitate and support grassroots efforts to mobilise programmes that foster membership, increase influence, meet needs, define aspirations and develop a shared emotional connection among community members; and serve as a catalysts for change and for engaging individuals and the community in decision-making and action.

Governments, Political Leaders and International Institutions: must tackle discrimination by constructing policies and passing legislation that effectively creates justice and promotes the dignity of and reduction of stigma and discrimination against people. Discrimination on the grounds of mental illness, ethnicity, disabilities and sexuality must be outlawed and appropriate international legislation developed through the United Nations and enacted by all member states. Governments can also exert considerable influence by ensuring that they allocate finances to organisations which can demonstrate their positive efforts to address stigma.

Public Health: Public mental health is relatively new for many nations and requires some explanation before it is understood to the same degree as public health more generally. Public health workers must engage the community in health decision-making and improving community participation in health promotion and health protection; advocate on behalf of the communities for equity of funding and resources, education at all age levels - schools, employers, media and reporting, integrating mental health into generic primary health care.

Media: The media needs to be aware of the effect of their depiction of issues where mental health is involved. While being truthful, the media must be careful not to produce reports or programming which depict those who are experiencing mental illness as individuals to be ridiculed or treated as inferior.

Business: Businesses should acquaint themselves with the fair employment practices of their country or state and apply them justly and equitably. Most people, at some point in their life, will experience mental health challenges and the knowledge of such issues should not be used as excuses or reasons not to engage individuals.

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