

The Centre for Applied Research and Evaluation-International Foundation Global Position Statement: Stigma, Mental Illness and Diversity

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Abstract: *Over the millennia, humans have struggled to understand mental illness. Despite scientific advances, we remain perplexed by the diversity and subjectivity of psychiatric disorders. The way that psychological distress or mental illness is understood and subsequently labelled has a number of consequences for the individual, their family and the wider society in which they live, which may also have relevance for how stigma is attributed and experienced. The labelling used may affect the way service users may feel about and internalise their health status. This labelling may also affect the successive actions taken as a result of the descriptors used and the 'resources' subsequently allocated.*

Industrialised societies have become materially sophisticated, but there is still extensive stigma attached to human diversity, including mental illness, despite diversity being an essential part of nature. Humans have evolved from simple to complex biological beings, living in increasingly large and varied societies. As human complexity grows, so, inevitably, does the diversity of individual experience within these groups. However, 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 group norms (e.g. Hall and Jefferson, 1976), or are unable to respond effectively to accepted norms, may be stigmatised and either marginalised, persecuted or forced into acceptance (e.g. Corrigan and Watson, 2007). Fear, isolation and anxiety may underpin these processes (Corrigan and Watson, 2002).

Key words: *stigma, mental health, diversity*

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

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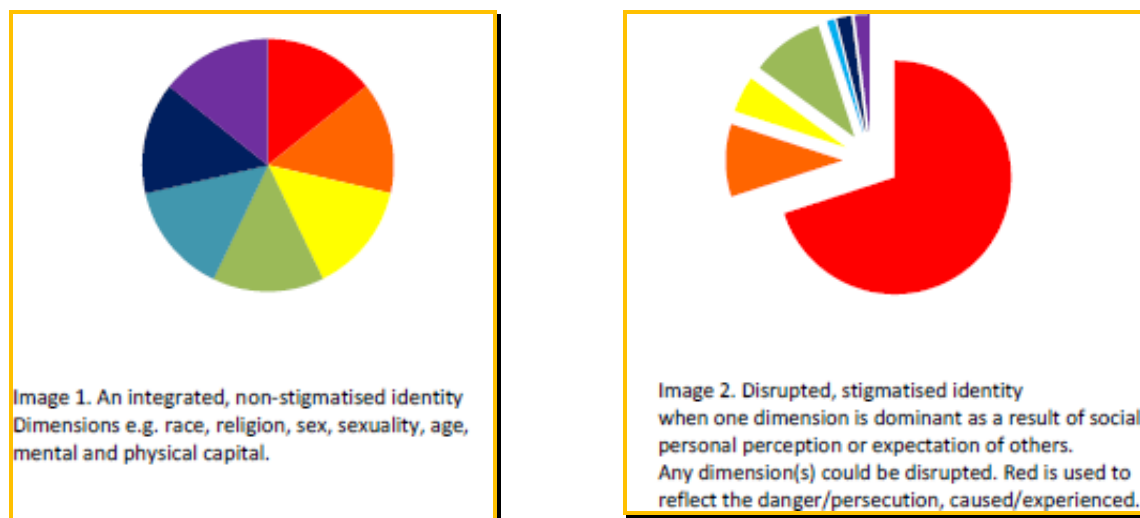
INTRODUCTION

Paradoxically, the same processes are exploited by leaders with extreme ideologies, to radicalise people who are impressionable/vulnerable into becoming members of a cult or extreme group, and to carry out acts of terror including self-sacrifice with the promise of reward in the afterlife. Figure 1

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(Yoganathan, 2015) illustrates a healthy individual, where aspects of their identity are in harmony. Figure 2 shows the consequences of one or more aspects of their identity becoming dominant, resulting in stigmatisation (Yoganathan, 2015).



The concept of stigma can be traced back to Ancient Greece when a person who had contravened the rules was physically marked out from everyone else. 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 are usually pejorative and some have become politically unacceptable (Yoganathan, 2015). Howe et al., (2014) and Dinos et al., (2004), record the impact on individuals of being stigmatised because of mental illness.

No high profile anti-stigma campaign has attempted to capture the interaction of being subject to more than one form of stigma; instead, different stigmas have been targeted in isolation. Can the stigma of mental illness be dispelled without dispelling a number of other stigmas, too, including, but not restricted to, gender or race related? If all anti-stigma campaigns worked together holistically, then different stigmas could be tackled simultaneously (and not in silos). We might then start sharing with the public information that has hitherto remained in the domain of academics and health professionals e.g. the fact that lesbian, gay, bisexual, and transgender (LGBTQ+), and black, Asian and other minority (BAME) groups (as well as other stigmatised groups), are significantly more likely to have mental health problems (Institute of Race Relations, 2019), including suicidal thoughts. Whilst this united approach might dilute the simple message that a discrete anti-stigma campaign can deliver, we believe that all campaigns to tackle social exclusion should educate the public on the impact of stigma on individual mental health (Evans-Lacko et al., 2016).

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 survey, 2016.p.199) 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 recognise and accept that health is not only physical but also influenced by social and psychological (including spiritual) conditions (Careif, 2017). 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/service user) themselves to explain and accept 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 (Wariki et al. 2013), 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, political and commercial interests rather than objective, biological evidence, hence remain ambiguous. Table 1 tracks this expansion in categories of mental illness (Willis, 2015).

Table 1: Categorisation of mental Illness (Willis, 2015) Stigma self-harm and suicide

| Date | Organization | 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 can embrace both negative and prejudicial attitudes and also discriminatory behaviour towards people with mental health problems, including mental illness, suicidal behaviour and self-harm. Such stigma could on occasions be considered a life-limiting condition as the secrecy and shame it propagates may prevent 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 can exacerbate this (Maple et al., 2010).

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

STIGMA, DIVERSITY AND CHOICE

“Culturally sanctioned behaviour will give you less stress and thus be good for wellbeing in terms of mental health” (Careif/WPA Wellbeing survey, 2016.p.112). Survival of the human species requires food, shelter and procreation. Industrialised societies may offer some members choices e.g. whether to be a vegetarian or meat eater, drink or abstain from alcohol, follow a religion or be an atheist. Choice of alternative diet may be tolerated, but choices that are perceived to threaten the established norm are likely be stigmatised (Corrigan and Watson 2007). 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 (Atlas et al., 2008), but are these purely narcissistic or do they reveal fear of diversity and the challenge this brings to the status quo?

SEXUAL DIVERSITY IS MORE COMPLEX:

Some may perceive this to be a choice, but others would argue that it is part of human diversity i.e. 'natural'. Nevertheless, stigmatisation is manifest once more in the use of offensive terms e.g. 'bent', 'queer', '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, survey 2016.p.133)

Sexual diversity is an 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. Alarming, homosexuality is seen by some, including in parts of high or middle income countries 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 (Corrigan et al., 2002). 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 disability, poverty, substance misuse, age, gender and so on. There is considerable 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 & Dinos 2011; Sonderlund et al. 2017).

"I am a woman - I struggle to be recognised at times in a male dominated-world." (Careif/WPA Wellbeing, survey, 2016, p. 112)

Stigma and the shame associated with it, whether based on gender, ethnicity, religion, mental or physical illness or disability, cannot be separated from politics, economics and power relationships within society. The current globalised economic system, with its benefits for some, is also contributing to rising financial and social inequality (Alvaredo et al., 2018). Human society is facing unprecedented threats and anxieties in the shape of climate change, global terrorism and technological warfare. In this context, prejudice and stigmatising of groups of people within society can be understood as an unconscious psychological mechanism deployed by dominant groups to transfer onto others their feelings of anxiety, vulnerability, inadequacy and shame (Yoganathan, 2015).

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 (Yoganathan, 2015). 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) or 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 (Corrigan and Watson, 2002). Any economic or 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 Nazroo & Becares, 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 associated traumatic events, whether based on gender, ethnicity, mental or physical disability, or being a member of a stigmatised social group, can cascade down through generations. Intergenerational transmission of trauma can be a major cause of the manifestation of anxiety, depression and other psychological symptoms in young people (Bhui, 2016). Unprocessed trauma within societies and within families may cause dysfunctional relationships, as is

painfully illustrated by survivors of the holocaust (Felson, 2017). Domestic violence and marital breakdown may on occasions be higher in marginalised, immigrant populations (Erez, et al., 2009) with possibly 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 may signify a period of disorientation, loss and readjustment, as well as periods of hope and optimism. Unprocessed traumatic experiences may lead to disturbance in individuals and families (APA, 2012). This is doubly reinforced when it has been precipitated by genocide, war, occupation or political oppression (Yehuda 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’ are intended to reduce the stigma but, sadly, can have 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 (Yoganathan, 2015).

Another paradox lies in the use of diagnostic labels and definitions. These are essential for scientific understanding and research in the field of medicine, although not without their critics (Timimi, 2014). 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 illnesses (Maudsley Debate 2013).

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 survey, 2016, unpublished quotation) 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 related 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 by reducing complex cases to the contributory factor that offers the most measurable outcome.

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 survey, 2016. p.115) A dialectical process implies dialogue between multiple agencies: government, religious and community leaders, teachers, health care professionals, patients and carers. As beliefs and values are formed during our early years, we propose that health education should be mandatory and should include unambiguous approaches to mental illness and human sexual diversity.

Careif also acknowledges that changes to certain beliefs and values 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 gain confidence and empower themselves, thereby becoming free from this destructive cycle. 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 way of viewing things. We must also be careful of the language we use both academically and in regular speech, including avoiding professional jargon which may not always be understood by everyone, wherever 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 wider society. Thus, not only do they need to confront stigma from society in general, 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 levels (social, cultural, collective and individual) towards a position of acceptance. We acknowledge that for the cultural, collective and individual, movement towards acceptance is easier said than done, especially for those from minority groups (ethnic, racial, sexual etc), as in addition to the stressors associated with mental illness, people may face the micro and macro aggressions associated with racism and discrimination (Corrigan and Watson, 2007).

Societal stigmas and aggressions related to ethnicity and mental illness may contribute to anxiety (Hopkins & Shook, 2017) and even though ethnicity may act as a buffer against the negative consequences of anxiety for some people, the stigma associated with mental illness may deter individuals from seeking aid. 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.

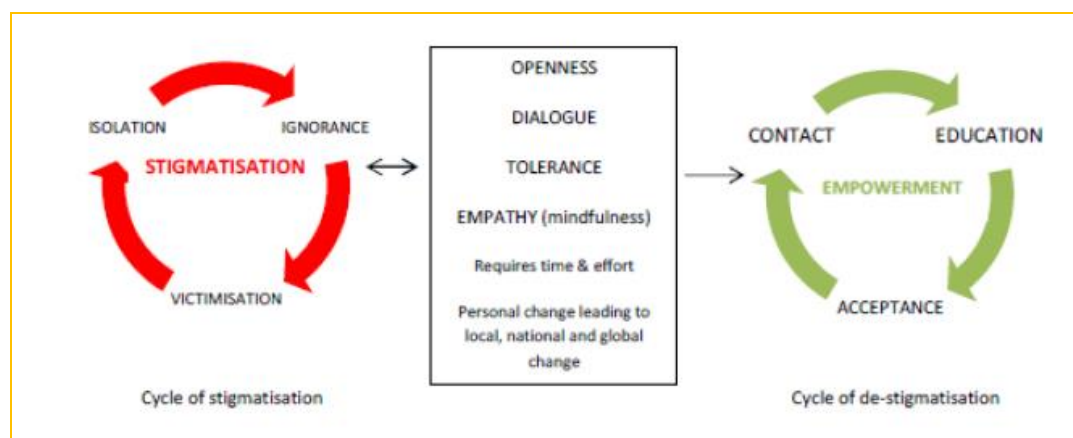
Careif, through its advocates, will continue to inform and teach the public. There can be a perception that those with mental illness are of lower *socio-economic status*, inferior and suffer societal restrictions (Tzouvara & Papadopoulos, 2014). It is quite possible for individuals to demonstrate empathy towards those undergoing mental health difficulties and still engage in stigmatising behaviours. The degree and type of stigma varies by culture, therefore the message must be tailored to the norms and realities of the context, if it is to maximise the probability of being accepted (Dinos, 2015). For this reason, medical students and all mental health professionals should be taught the importance of 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 : Tribe 2014).

Careif will use its influence to bring attention to the relationship between citizens with mental health challenges and law enforcement personnel. Police and prison services are often called to respond to incidents and disturbances in which the mental health of the individual is a factor. A lack of training in, and comprehension of, mental health problems can result in mentally ill people being stigmatised and treated more harshly than others (Schulenberg, 2016) which can lead to unjust criminalisation.

The figure below reminds us of the process required to move from stigmatisation to empowerment of the individual.

CAREIF CALL FOR ACTION:

A poor choice of words can perpetuate stigma, constrain thinking and reduce help-seeking behaviour. Stigma can kill and Careif calls upon people in all sectors to play their part in tackling and eradicating the stigma surrounding mental illness. In addition to those already experiencing mental health problems, Careif suggests we work with groups who are often marginalised by society, like LGBTQ+, BAME and homeless people, who experience additional forms of inequality and discrimination.

Figure 3: From stigma to empowerment (Yoganathan, 2015)**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 in them by patients, their carers, families and others. Professional bodies and service providers must develop strategies and plans to reach more vulnerable groups, often euphemistically called ‘hard to reach’ groups, through better training of health professionals and 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 may have an equal contribution to make in supporting people living with mental illness and their families or 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 and to 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 catalysts for change and for engaging individuals and the community in decision-making and action.

GOVERNMENTS, POLITICAL LEADERS AND INTERNATIONAL INSTITUTIONS:

They must tackle discrimination by constructing policies and passing legislation that effectively create justice, promote dignity and reduce stigma and discrimination against people. Discrimination on the grounds of mental illness, ethnicity, disabilities, age, religion 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 a relatively new concept 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, and 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 need 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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