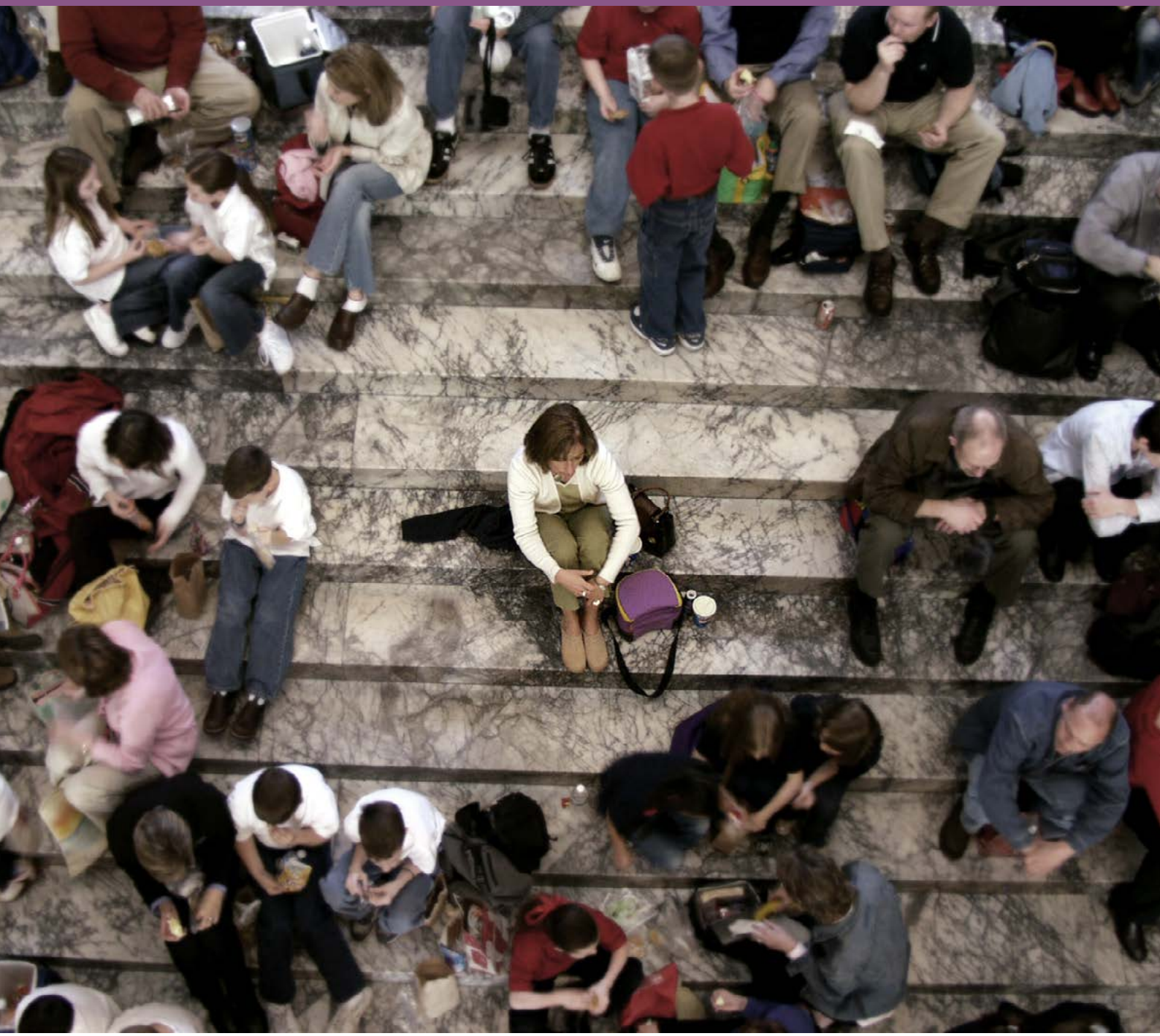
One Stigma or Many?

By Merinda Epstein



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This presentation was delivered by Merinda Epstein to the THEMHS Conference in May 1995.

All stigma is potentially destructive. It is useful to understand that there are multiple stigmas which operate differently in different settings. Some of these stigmas are born out of a social feat of difference and some are born out of a medicalised society which fails to treat seriously those things which appear to have dubious organic roots. Some stigma comes from those we turn to for help and some comes from our bosses, our next door neighbours and our friends. Some stigma comes from the direct actions of others and some comes from the fear that we carry around in us and is generated from inside ourselves. All stigma is based to some degree on ignorance, to some degree on social control, to some degree on intolerance, to some degree on our social inclination to group people in ways which allow us to find order in a complex world, and to some degree in our personal preparedness as social beings to protect our own mental health by defining others as essentially different from ourselves. We need to systematically work together towards minimising the paralysing secondary effects of all the different stigmas. Blame, intolerance and judgement diminish everyone and do nothing to promote health.

When people talk about the stigma of mental illness or serious emotional distress, they often do so as if there was only one entity. However, an argument can be put forward that there may be different varieties of stigma; stigmas which may in fact at times tug in opposing directions. It is important that we untangle what we really mean by stigma if we are going to work towards an effective change in the attitudes held towards people who continue to suffer twice when they become mentally ill or experience serious emotional distress.

What is stigma?

Most people who have experienced stigma continue to have some difficulty identifying exactly what it is they are experiencing. There is a general understanding, however, that stigma feels bad. There is also a common belief that it comes from 'the society'; that is, from others whom people who have a mental illness or experience interact with. There is a shared understanding that stigma comes out of others' judgements (whether this is openly acknowledged or not) and represents beliefs and attitudes which are based on ignorance, misunderstandings, fear and sometimes others' powerlessness. It can be found in psychiatric hospitals and clinics as well as within the general community. It happens in the doctor's office and it happens in the supermarket; in the casualty department of the general hospital and in the local church hall; in one's home and in one's workplace or on the street.

Generally consumers can identify a set of human behaviours which 'signpost' that they are being stigmatised. For example, many consumers talk about the way people fail to make eye contact with them or find it really difficult to engage in any sort of conversation about mental illness, psychiatric hospitals etc. The use of collective nouns such as 'schizos' or 'depressives' is another identifying trait. Others talk about the way that those who have not been through an experience of mental illness or serious emotional distress often offer simplistic and often destructive advice such as "she just needs a good kick up the bottom" or "she needs to pull her socks up" or "if only she didn't think about herself all the time".

Others talk about stigma in terms of being treated like a child, being told what to do all the time or being unnecessarily monitored and thus unable to make the same range of good and bad decisions as every other human being who inhabits our social world. Consumers complain about it; carers complain that they too often feel judged and misunderstood; and mental health professionals also experience it when their work is undervalued or becomes the butt of

insensitive jokes which undermine both their clients and their professionalism. The impact of stigma can be profound. It can add stress that actually promotes 'illness' and it certainly adds unnecessary pressure to lives which may already be experienced as disablingly stressful.

Stigma from outside the individual has the capacity to reproduce itself within the individual 'victim' and then, if unstopped or unproblematised, can generate its own secondary trauma. This of course magnifies the original problems because social beings absorb others' judgements, others' shame, others' fear and others' disgust and reproduce it, understandably thus developing self fear, self disgust and self judgement or shame.

Why does a society have stigma?

If stigma is such a negative thing, with such negative consequences for those people who are on the receiving end, interesting questions need to be asked about why it happens. What possible social gain is achieved by its continued existence; indeed, by its coming to be in the first place?

Stigma is not a necessary evil. It does not have to co-exist with mental illness or emotional distress. The Murri people of northern Queensland have a word for people with mental illness. If you allow this word to roll off your tongue you will hear it as a lyrical, respectful word. Mental illness is not stigmatised in this cultural setting in the same way as it is in white society. Stigma is therefore not a product of mental illness but rather a social construction that only makes sense within particular social contexts.

Any society by its very nature must have rules. Otherwise there could be chaos. These rules were in existence before we, as individuals, entered the world., However, as individuals we help to construct and re-create them These social rules operate to control behaviour within parameters which are deemed to be socially acceptable within a particular society. Some rules come in the form of laws by which we live, but there are other mores which we, as a society, create to maintain order, which tell us which sorts of behaviours bring social, economic and political rewards and ones which do not.

As children we learn these behaviours fairly effectively. When a child transgresses they are reminded in subtle (and sometimes less subtle) ways that their behaviour should be modified. When they do the 'right' thing they are rewarded. These subtle and less subtle things which we put in place in our society to control behaviour take many forms: people can be punished, ostracised, told how to behave, ignored, distracted etc. Stigma is an effective social sanction. The enactment of stigma can be seen to take place against those groups of people which we, as a social group, perceive may threaten the viability of our society. In other words, it has a social value. And thus the adverse effects of social stigma in our dominant white culture are felt not only by those with mental illness but also by other marginalised groups; black Australians, people who don't speak English, those living in poverty, those without work, people who are illiterate, those with other disabilities, those have been in gaol, gay men and lesbian women etc.

Societies also create institutions which are slow to change – institutions which, among other things, uphold values and belief systems. Whereas it could be argued that the formal education system, for example, may have a role to play in questioning and reworking value constructs, this cannot be said of the media, which is driven by the need to sell its product and therefore reproduce the values that those who may wish to buy already hold. It is for this reason that the media has become a particularly important institution in the reproduction of values.

It makes good business sense for some media to choose to publicise 'myths' about mental illness. We seem to be fascinated by the bizarre and the violent. Equally potent, however,

are stereotypes about 'goodness' and 'badness'. We read in weekly publications good news stories about those who 'bravely' remain cheerful under great duress; the child with cancer who continues to smile; the man who loses both legs and doesn't give up on life. We feel compelled by such stereotypes to present to the world in ways which hide our sometimes very real feelings of anger, despair and profound psychic pain. In such an ideological milieu those among us who feel hopeless, for example, will also feel profoundly ashamed. This is not necessarily intended but it is an example of institutionalised stigma.

Stigma can also be seen to serve a useful economic purpose because it acts as a 'natural' delimiter on service demand. This is not unique to mental health services. We can see it equally well in community attitudes towards people who are unemployed in our society. The worse we can make them feel as jobless people, the more pressure we place on them (theoretically at least) to get jobs and therefore not be a drain on the state. In mental health service provision, the same principle applies. Effects of stigma such as shame and fear operate to create a silence around mental health problems which restricts the numbers of people who feel brave enough to seek services and thereby risk the stigma which such action might elicit in their lives. From the point of view of governments this might actually be a useful arrangement except when the consequence of not seeking services is an increase in 'on the street' symptoms which worry the public (as compared to pain which worries the individual). At this point, people's reticence to seek services has the potential to become politically damaging.

Why do we, as individuals, stigmatise others?

There is a risk in seeing stigma only as a social (rather than an individual) responsibility. For most of us it is easier to think that stigma is perpetuated by those 'out there' – that amorphous blob of others who collectively make up society. It is harder for us to recognise that stigma is perpetuated by ourselves. It can be argued that one of the defining characteristics of stigma is that those of us who stigmatise do so because we all too often fail to personalise our understandings and instead use classification systems to order the increasingly complex social world we find around us.

For example, you can only think that all people with mental illness are violent if your sister doesn't happen to have schizophrenia. If your sister has schizophrenia you might continue to believe that all people with mental illness except your sister are going to behave violently but you will no longer put all people with schizophrenia into that category. More likely, you will start to meet some of your sister's friends and then your belief system will be modified again and you'll now know that of course Jane isn't violent and neither are her friends Phillip, Heather and Serap, but you remain unsure about Craig (and you know that you are still a little scared of him sometimes), as you are about your father's brother Phillip, who has never experienced any mental illness but frequently gets drunk.

It follows then that the more that people with mental illness make decisions to keep their experiences secret (because of stigma), the less likely we all to find opportunities which will help us to test our belief systems. Thus stereotypes are perpetuated and myths are enshrined. Neither does it help the cause of people with mental illness or serious emotional stress and those they love to deny the reality that some people with such illness sometimes do look different and sometimes do behave in ways which don't make sense to others and sometimes smell or talk to themselves or are difficult to live with. People see this for themselves. However, it does make sense for people to tell their stories; to talk about the reality they were experiencing when they made the decision not to eat or not to bath; to talk about the side effects of medication and how these are not mental illness but something else; to talk about 'normal' things like loneliness and sex.

Stigma is often a product of deep fear. It is often easier to avoid encounters with people whose lives seem strange, whose thinking may seem different or whose very presence forces us to question our own cherished 'sanity' or the health of our world or both. Mental illness is both too outrageously different and too alarmingly familiar to allow many of us to confront it without constructing a protective barrier around ourselves in order to deal with it. We all can feel scared when people present in the street affected by medication which produces side effects that most of us mistake for symptoms and thus whose movements and facial expression can take on an almost 'evil' appearance in the eyes of those of us who do not yet adequately understand.

It is also scary when we see the self-hating and despair-ate behaviour of others who have been treated very badly in this world. We do not particularly want to know that we, as participating member of this society, are responsible. It is scary when we are confronted with the awful things that we as humans can do to one another. Often this protective barrier we create to protect ourselves is made of bricks of distance or disbelief. We thus construct people with mental illness or serious emotional distress as essentially different from ourselves and this has the awful capacity to undermine their humanity.

Stigma is often based on ignorance. As individuals we form our belief systems and values from the experiences which have made up our lives. We have no other easily accessible tools with which to made sense of the multiple realities which surround us. Thus, as we move through the world we 'see' it through eyes which we sometimes believe see 'facts' but which actually sieve all our experiences through our internal meaning systems, which are, of necessity, limited. Therefore if we have never been really depressed (or lived closely with someone who has been really depressed), for example, it is very hard for us to understand the awful reality of such an experience.

As good natural scientists we look for signals which would tell us that this person who is telling us they are depressed is different from us. We believe that this outward sign of difference may offer us a key to understanding, but of course we find none because depression often takes place entirely inside the outer package of human presentation. This person looks and sounds normal. We use our own experience, then, to make sense of what we are seeing and hearing. We 'know' that we wouldn't dwell on feeling rotten. We 'know' that we would 'pull ourselves together and get on with it'. We then make judgements about this person who doesn't make any sense to us. This is stigma. This person's reality is being denied. We judge so that we don't have to put up with this or feel embarrassed or try any more to make sense of something we perceive as non-sense.

Gaining 'expert' knowledge about mental illness or serious emotional distress may help to alleviate ignorance but it does not necessarily offer others any real insight which would make them less likely to stigmatise. Ignorance in this sense can be as profound among mental health professionals as among the people who live two doors down from the group home. Insight into what it feels to be powerless may be as important in the fight against stigma as knowledge about the effects of different medication regimes. Insight into the effects of being treated in an undignified way may be as important as insight into mental illness from a medico-scientific perspective.

Profound learning, in this sense, comes from getting opportunities to hear and share with people who have actually experienced mental illness and those they love; to hear the story from the inside. Equipped with this knowledge (and a recognition that by the grace-of-god-go-I) we are better able to reconstruct our own belief systems and to see the world differently. When we are genuinely able to do this we will be less likely to add our burden of ignorance and fear to the lives of those who already have quite enough with which to deal.

Those who stigmatise rarely do so maliciously. In a social context stigma often operates to protect the mental health of those who do the stigmatising. If feeling OK about yourself necessitates that you perceive, for example, material success, independence from needing help from others, overt emotional strength (the ability to deal successfully with stressful situations) or the ability to be stoic or cheerful under duress as definers of self worth, then it is inevitable that you will view others who are (by definition) unable to claim these same attributes as inferior, to be pitied or to be judged.

It is useful to ask ourselves what would happen if we were to take the issue of stigma seriously enough to radically change the way we value ourselves and the other supposedly 'healthy' people in our society. Can any of us have ways of valuing others which are truly genuine without re-evaluating the way we have learnt to value ourselves?

What is stigma to one may well be power to another

The way stigma operates in our society is not necessarily straightforward. A minority of people who have experienced mental illness or serious emotional distress claim not to have experienced stigma at all. It is possible that for a small percentage of those who hold power (economic, political or social) or those who start with a very healthy self image there is less likelihood of experiencing the powerfully negative effects of stigma, or at least there are greater opportunities to compensate for it.

Some professionals in the field argue that feeling stigmatised is symptomatic of illness. They thus unintentionally perhaps devalue the suffering involved and quite intentionally handball the responsibility for the consumer's feeling of awfulness back to the victim rather than accepting responsibility for the part they (and others) may play in contributing towards it.

Stigmatising can also seem to be a way in which we can hold our own place in the world. Sometimes it comes from other relatively disempowered groups or people in society. In common parlance, we could call this 'kicking the dog'. In an effort to reclaim personal (and sometimes group) power we attempt to situate ourselves in relation to other groups in society. Thus the person with chronic back pain argues vehemently that it isn't psychological in the hope that others will take their pain seriously and desist from judging (stigmatising) them, but by so doing, they, in turn, stigmatise those who do experience serious psychological pain.

Similarly, groups representing people with physical disabilities sometimes stigmatise those who represent people who can be seen to have psychiatric problems by ignoring them or treating such disabilities differently. The speakers from the peak consumer group representing people with intellectual disabilities start their public speech by categorically stating, "We're not loonies," and the people from the peak consumer group in mental health start the ball rolling with the claim, "We're not dumbos"!

Getting the stigma off your back

It would be naive to believe that people who have suffered from mental illness or serious emotional distress (or who have suffered along with their family member or loved one) don't stigmatise others who have suffered equally (if sometimes differently). Indeed, most of us both feel the awful consequences of stigma and sometimes stigmatise others in an effort to feel better about ourselves.

Mental health is not an area which lends itself to solidarity, unfortunately. If it did, combating stigma would be rendered much easier. Intriguingly, perhaps, part of the reason for the divisions which exist are created by the stigma in the first place – a stigma which has meant that mental health has not been a high priority. This has forced people with different problems

to compete for resources which remain inadequate. Stigma has meant that people haven't compared notes openly and have been historically blamed for their own suffering in a way that does not happen in other areas of health care. Stigma has had the effect of casting blame on families and sometimes unnecessarily dividing them. The combined consequences of this plus the unfortunate and sometimes horrific history of abuse of people with mental illness, and abuse of the system by people whose motives for incarcerating others have not always been 'pure', has sometimes led to people and groups within the mental health arena attempting to find their own legitimacy (and dignity), unfortunately, by placing themselves in a way that stigmatises others.

A friend was speaking to me the other day and in absolute desperation and despair said, "Why do I get treated as though I am doing all this on purpose? Why do they think I am so bad? If only I could name it. If only I could find a 'real' illness then people might start to treat me with some respect. I hate them. How do I stop them blaming me? I hate myself so much. I wish I had schizophrenia." Another friend who was standing next to her at the time and, like me, feeling with her and for her quietly put her arms around this young woman and said, "At least you have been strong enough not to go psychotic. It is a strength. For god's sake, we are really proud of you. Don't let them get to you like this." I was both shocked and humbled by the look on that young woman's face. This was quite obviously the first time in her adult life that she had heard her refusal to go psychotic named as a strength.

Two days later I heard another woman talking and she said to the two people beside her, " Well, I don't know about them [people experiencing psychosis]; mine is not like that. I never went mad or anything. Mine was just ...".

The very same day I heard a young man talking on the radio. He spoke beautifully about his experiences of having a psychotic illness but when asked a question about schizophrenia and violence he answered it by claiming that violence was perpetrated by people who just had 'personality disorders' and this didn't have anything to do with mental illness.

In all these instances people were trying to find their place, a respectable place, within a social world which does not necessarily respect and within a world of illness and disability which is often contradictory. The first women had been stigmatised to the point of damage within a state system of health care which has constructed legitimacy around diagnoses and which over a long period of time had totally failed to acknowledge her pain as legitimate, genuine or serious. She was a victim of systemic stigmatisation within mental health services themselves. A potential solution was found for her by a sensitive and insightful friend but only by counteracting one stigma with another – by constructing a potential to see psychosis as a deliberate act, which, of course, stigmatises another whole group of people with mental illness. In the second instance a woman was attempting to find legitimacy by distinguishing herself from the 'real nutters' by claiming 'just a little bit of mental illness', getting the stigma off her own back by reinforcing its damaging impact on others. And in the third instance the young man effectively distanced his own experiences from a misinformed stereotype of violence by labelling and stigmatising another whole group of people; by using a language which reinforces blame and by failing to mention the gender and social class factors which should inform any sophisticated discussion of violence in our community.

Different experiences of stigma

When labels become so big that people can no longer see the individual behind, them this is stigma. When a person becomes a 'schizophrenic' or a 'bi-polar' and a 'bi-polar' becomes someone who is, by definition, permanently out of control, to be monitored, not to be trusted, crazy, etc, then this is stigma. However, equally damaging is the stigma of nameless pain or

when a deeply damaging and judgemental generic catch-all such as 'personality disorder' gets used to blame the victim in an area of mental health care which medical science has thus far failed to adequately understand. We stigmatise others often when we feel powerless. All of us find ourselves at times overwhelmed when we don't yet have an answer. Unfortunately, stigmatising those who appear to be creating the puzzles is as damaging as stigmatising others by the language which accompanies the answers that we believe we have found. It is stigma when the label becomes the person and it is also stigma when someone's deep and serious distress is trivialised because we haven't yet adequately named it.

Similarly, the overt symptoms of psychosis can create fear and some of the worst stigmatisation associated with mental illness. Equally damaging, however, is the stigma associated with the hidden pain of depression, for example, which cannot be seen on the outside and which is often experienced on the inside as a living hell.

Those of us who have experienced getting on to a train and feeling the atmosphere change – as people watch us and then all the eyes are diverted into the nearest newspapers and children's hands are quietly grabbed and held tight and everyone is trying to be so polite and not make a scene and not notice that we are there – know about the potency of stigma. So too do those of us who are told in myriad small ways that the suffering, pain and mental anguish we have perhaps struggled through over many years is not 'good' enough to be taken seriously by those who provide the services and through this are given clear messages that we are bad or just useless. So too are those of us who cannot adequately explain to others how awful we are feeling; who have found that words are not enough and are desperate for (and sometimes jealous of those who are 'lucky' enough to have) overt symptoms.

Stigma and politics within mental health

Those of us working towards changing attitudes are sometimes caught ourselves within the contradictions which surround us. The most obvious way to promote greater tolerance and understanding is to claim 'illness'. Unfortunately, defining people as ill may have a stigmatising quality of its own. It also has the unfortunate capacity to disenfranchise from any chance of respect those among us who cannot so easily support such a claim as the reason for our distress and pain. In a judging world another way of attempting to promote greater understanding is to claim 'disability' and fight for the rights of those who are disabled, but again this has the potential to disenfranchise those who are not, or who do not want to see themselves as disabled but whose pain is very, very deep and often misunderstood.

If stigma can be seen to be derived at least in part from ignorance, the obvious thing to do is to educate the public. However, we cannot afford for our messages to turn into slogans and they must be handled with sensitivity and care. For some people, serious mental distress is a direct result of horrible things that have happened to them (or their people) in this social world of ours: incest, rape, torture, distressed families, the removal of children, social dislocation, dispossession, war and tragedy. For others, mental illness is the result of a chemical imbalance in the brain which may be triggered by stress but which becomes and is maintained by a biochemical agenda. For others, mental distress is a throbbing and very alive combination of all these factors. People with mental illness, and especially their families, have suffered altogether too much from attitudes which wish to look for social or psychological explanations – coat hangers for blame. It is stigma to blame families. It is a stigma which causes great and unnecessary pain. However, for others who, in order to recover, need to name a reality from their past which was silenced and allowed to fester into adulthood, who were asked to keep secrets too horrible to contemplate and who all too often had their reality denied and obscured, the message to the public is an altogether different one.

It is dangerous to view stigma in hierarchical terms. All stigma is potentially destructive. It is much more useful to understand that there are multiple stigmas which operate differently in different settings. Some of these stigmas are born out of a social feat of difference and some are born out of a medicalised society which fails to treat seriously those things which appear to have dubious organic roots. Some stigma comes from those we turn to for help and some comes from our bosses, our next door neighbours and our friends. Some stigma comes from the direct actions of others and some comes from the fear that we now carry around in us and is generated from inside ourselves. All stigma is based to some degree on ignorance, to some degree on social control, to some degree on intolerance, to some degree on our social inclination to group people in ways which allow us to find an order in a complex world, and to some degree in our personal preparedness as social beings to protect our own mental health by defining others as essentially different from ourselves. We need to systematically work together towards minimising the paralysing secondary effects of all the different stigmas. Blame, intolerance and judgement diminishes everyone and does nothing to promote health.

THEMHS Conference

THEMHS, originally an acronym for The Mental Health Services conference, changed its name to THEMHS Learning Network in 2004. The first THEMHS conference was held in 1991. It was originally set up by a group of progressive psychiatrists seeking to place the emphasis on public psychiatry. In 1994 a 'Consumer day' was held for the first time, in 1995 an Indigenous day, and in 1996 a Carers' Day. Every year the conference is held in a different city in New Zealand or Australia.

Over the years the voices of consumers and carers gained ascendancy and the clinical voice widened to emphasise a multidisciplinary approach. Awards are presented annually to recognise and celebrate excellence in public and community psychiatry. The Gold Award for Consumer Achievement was awarded to Our Consumer Place in 2012.

THEMHS Learning Network is recognised internationally for its:

- Inclusion and respect for consumer, indigenous and carer knowledge
- Progressive and transformative ideals and outlook
- Equal respect for the knowledge and practice of all workers and all clinical groups
- Recognition of consumer and community workers
- Multiple approaches to enabling people without incomes to attend and be supported
- Respect for science and rigorous research
- Summer Forum, emphasising an academic agenda
- Attempts to encourage and support inexperienced presenters.