The challenges involved in tackling the stigma of mental illness

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It should be pretty clear to anyone who reflects on the human condition that across society - and within each of us - there are struggles aplenty. Included in this are bucket loads of stigma associated with a range of differences. Sexism, racism, and homophobia come to mind but there are plenty more associated with religion, age, class, ethnicity, health and quite often too, to day-to-day appearance and behaviour. Each of us has a notion of who we are and where we fit, stigmatiser and stigmatised. We may feel empowered by who we are and where we fit. On the other hand, we may feel rejected and excluded because of who we are. We may even internalise that rejection and accept it as part of who we are. Just as importantly we may worry about the stigmatising we practise, recognising that it is wrong but lacking the courage to stand up against it. Perhaps this contradiction between what we "know and feel" and what we "say and do" is what Leonard Cohen had in mind when he wrote the following in his song Everybody Knows:

> Everybody knows that the boat is leaking
>
> Everybody knows that the captain lied
>
> Everybody got this broken feeling
>
> Like their father or their dog just died
>
> .... Everybody knows, everybody knows
>
> That's how it goes
>
> Everybody knows...

All too often, of course, it's in our interests or too daunting to see beyond the factors that divide us one from the other. As Dominican priest Timothy Radcliffe puts it in his reflections on The Parable of the Good Samaritan: "We love the members of our own family as ourselves, because they are part of who we are" but what about "the stranger"? "Within every society", he says, "There is fear of those who are different, who have different religions, different colours of skin, who dress differently, speak different languages. The invitation of the parable is to make them neighbours" and by so doing "to construct a society that does not yet exist"[1]. My challenge for today is to see what all of that means when considering the differences revealed by our mental states. My theme is that even though we have made progress in respect of the debilitating and destructive stigma associated with mental illness there is still plenty to do. In that regard, we need to be more realistic when it comes to our understanding of what drives it and, by

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[1] "The Parable of the Good Samaritan", Conference at Camaldoli, 30 June 2001

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implication, more radical when it comes to finding sustainable solutions. Stigma has deep roots in human nature and it's only by being radical, that is to say by going to the root or origin of things that progress can be made. I will argue that tackling stigma involves not just public education about the facts and personal connection with those who are ill but political and clinical support for evidence- based and individualised services. We need not just to inspire compassion but to guide it to produce demonstrated improvement.

A WELL-BEING AGENDA

However, in order to get the ball rolling, let me start with the World Health Organization's wonderful definition of health incorporated into its 1948 Constitution. It defines health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity". It has its limitations and it's clearly utopian in its aspirations but it does remind us that well-being matters - and not just physical well-being but also mental and social well-being. This was statement ahead of its times in a world more focussed on rebuilding economies ravaged by war. Jobs and economic growth were seen to be the key to it all, the quality of society and the environment taking second place in the equation of happiness. Put simply GDP was the king and queen of progress.

It all started to change in the 1960s and the foundations were laid for a deeper meaning of what it meant to achieve progress. The WHO's concept of well-being was given more attention by researchers, clinicians and policy makers. One set of answers was provided by psychologists Deener and Seligman who concluded that in order for life to be tolerable and happy we needed to:

- Live in a democratic and stable society that provides material resources to meet needs,
- Have supportive friends and family,
- Have rewarding and engaging work and adequate income,
- Be reasonably healthy and have treatment available in case of mental problems,
- Have important goals related to one's values, and
- Have a philosophy or religion that provides guidance, purpose, and meaning to one's life[2]

Perhaps we'd have something to say about the natural and built environment as well but that being said there's a nice mix of elements in their list - self and other, individual and community, citizen and state - and one way to follow up on the list is to compare nations on how they fare. Interestingly the Nordic countries always feature near or at the top in such "happiness league tables". Not only do they take their economies seriously they invest heavily in their societies on the basis of "the underlying values of egalitarianism, inclusion and care"[3]. As I will attempt to show an important step in tackling stigma in relation to mental illness is a community-wide commitment to these values; they can't just be add-ons in an otherwise GDP-focussed world.

All of this is a powerful reminder that it's not just our freedom and our material standards of living that matter but also our "inner lives" or the way we "feel, think, behave and interact with

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[2] "Beyond Money: Towards an economy of well-being", Psychological Science in the Public Interest, vol. 5, no. 1, 2004, p.25.
[3] Shirley Jackson, "Why Nordic countries top the happiness league", pursuit.unimelb.edu.au/articles

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other people" as the Australian Department of Health puts it on their website. This being said I would have preferred Diener and Seligman to have said "be reasonably healthy and have treatment available in case of mental illness". I say this because it's one thing to recognise the stresses and strains which come with life - and which need our attention - but another to acknowledge the distinction between these problems and mental illness. Mental illness, or should I say mental illnesses, are distinctive and powerful in their effects, whether we are talking about anxiety disorders, depression, schizophrenia or personality disorders. For those who suffer these "pains of the mind" as Richard Layard and David Clark[4] call them, happiness isn't like a consumer item to be purchased from the local supermarket. Trivialising it in that way, along with complex ideas like self-awareness and self-management - can operate in a perverse way, encouraging those who are ill to take a course perhaps as damaging as self-stigma induced isolation. It is important to ensure science - and all the rigours attached to it, are part of the mental health equation. It's one thing to say we need to act, another to ensure those actions are well targeted and effective. With this in mind note the around four billion dollars a year we as a community are devoting to complementary and alternative medicines and therapies - it's more than the entire health budget of the Northern Territory. Referring to the failure of many of these so-called wellness products to pass the test of effectiveness, Amy Corderoy, formerly health editor of The Sydney Morning Herald asks the right question about the ethics of it all: "What if all of those dollars were poured into some real wellness?"[5].

Now we all know - or at least we all should know - that when it comes to these matters of policy and priority there's always a number of factors at work, one of which includes the majority versus the minority (or minorities). It may be majority opinion or majority culture or majority interests, perhaps even majority prejudices but whichever way you look at it these things matter because in a democracy the majority has a powerful, if not always determining, role to play. Think of the different ways we might describe our democratic task - is it to bring about the greatest happiness for the greatest number or is it to ensure the least pain for the least number? If it's the greatest number that rules will the pain suffered by any minority be of sufficient interest and concern in the absence, for example, of an over- arching doctrine of human rights? Even the call to love our neighbour may be just that and not the person on the other side of the street or living overseas or with another religion or creed.

There are so many ways in which we can, and do, create an us and a them including the stigma associated with mental illness. This can reflect itself publicly as prejudice and discrimination or privately as diminished self-esteem and feelings of worthlessness. It adds to and complicates what are already serious problems associated with such illnesses. Given the significant number of illness types it's not surprising that stigma takes different forms. Sometimes those who are ill are stereotyped as weak, incapable, lacking in will and perhaps even indulgent. The question "why should we help those who don't help themselves" is often thought if not said. Sometimes it's fear that drives the stigmatising, those who are ill with conditions like schizophrenia framed as incomprehensible, dangerous and out-of-control. The behavioural impact can take four forms; "withholding help, avoidance, coercive treatment, and segregated institutions"[6]. It's worth noting here as well that the stigmatising behaviour attached to, for example, racism, sexism,

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[4] Thrive: The Power of Psychological Therapy. (Penguin Books, 2014), pp.34-36.
[5] "The sickness of social organisation", Griffith Review, Edition 56, pp.194-195.
[6] See Patrick Corrigan and Amy Watson, "Understanding the impact of stigma on people with mental illness", World Psychiatry, Feb 2002, pp.16-20.

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homophobia, or religious bigotry can be a key factor in the emergence and development of mental health problems and illnesses. In analysing it let me begin by describing the range of initiatives that have been taken to combat stigma and giving my estimate of how far we have come. How much progress has been made? How much is still to be done?

ANTI-STIGMA INITIATIVES AND THEIR IMPACT

The range of initiatives is many and varied, ranging from working face-to- face with those who are ill to counter any negative self-images they may have through to community-wide programs educating the public about "the facts" pertaining to the many types of mental illness. Self-help groups sometimes involving family and friends too have been created to not only share insights but also to advocate and educate. Campaigns have been devised to challenge stigmatising language and media representations of mental illness and to press law-makers to ensure discrimination is outlawed. Special efforts have been put into working with those on the front-line of service delivery whether health professionals of all sorts or police officers and prison officers. Indeed, all sorts of organisations, both government and non-government are to varying degrees attempting to incorporate understanding of mental health and illness in their workplaces. In all of this contact between the stigmatised and the stigmatisers has been found to be very important, if not crucial, in that it brings a personal dimension to an issue that requires it. It's a big mix of education, protest and contact, of intra as well as interpersonal efforts, of law or public opinion as targets and can be of a one-off or a continuing nature. Sometimes the focus is on trying to "normalise' mental illness as a part of the human condition, but one that can be successfully treated. Sometimes it's just a case of reminding us all that human beings are involved and along with that their dignity and their rights[7].

Before giving my estimation of the current state-of-play let me make a number of important distinctions that have been raised by those who have researched these initiatives, firstly, between general knowledge we may acquire about mental illness as a health condition and attitudes towards it. A considerable amount of relevant knowledge doesn't necessarily lead to an absence of stigma. For example, it's been found that wider understanding of the biological causes of illnesses like schizophrenia may in fact harden rather than soften attitudes, leading to a "greater desire for social distance". Why? Because it feeds into the view that the mentally ill are "almost a different species"[8].

Secondly, we need to distinguish between attitudes and behaviours. "The challenge", as Dr Alan Rosen has written, "is to be able to change behaviours, not just nominally shift attitudes"[9].0n the surface, we may care but deep-down and in our day-to- day functioning where it matters to those who are ill we harbour stigmatising doubts. In saying this I'm reminded of the distinction often made between the "active wise" and the "passive wise". I'm reminded too that empathy may express itself as paternalism and disempowerment. Corrigan puts it this way: "Anti-stigma

[7] For a good summary see Nicholas Rusch, Matthias Angermeyer and Patrick Corrigan, "Mental illness stigma: Concepts, consequences, and initiatives to reduce stigma", European Psychiatry, Vol. 20 (2005), pp 529-539.
[8] Ibid, p. 535.
[9] Email correspondence, 29 March 2017. My thanks too to Dr Rosen for his insights and for providing me with reference material on stigma.

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advocates need to cultivate empathy that leads to parity, not to condensation and exaggeration of difference." The goal, he says, should be "parity not pity"[10].

Thirdly we need to distinguish between intentions and consequences. As noted above we need activity coupled with wisdom, a part of that wisdom involving judgement about the actual as well as the intended consequences of what we do to combat stigma. Human response to seemingly straight-forward messages can be complicated but even more so when we are talking about a condition that can take many different forms. The lessons we have learned from the experience as opposed to the theory of implementation include "the limited benefits of education especially when compared to contact, beating stigma is more that changing words, beware pity as a message, understand the competing agendas of stigma, replace ideas of normalcy with solidarity, and avoid framing self-stigma as the problem of people with mental illness and not of society"[11]. Corrigan stresses that understanding these complications should in no way hold us back from taking steps to address stigma, rather it urges us to do even better in design and delivery.

All this being said I believe that as a result of all of these initiatives, some more than others that is true, we can report valuable rather than self-defeating progress in respect of the public's knowledge of mental illness and at least some of its causes and consequences. I'm not talking here about detailed, in-depth knowledge but general knowledge just as we might say there's general if not in-depth knowledge about the existence of climate change. This is the result of many awareness campaigns, increasing contacts, direct and indirect, between those who are ill and others, and powerful advocacy by those who care. Our free and open society isn't perfect, far from it, but it has a capacity to locate and transmit useful knowledge to its citizens.
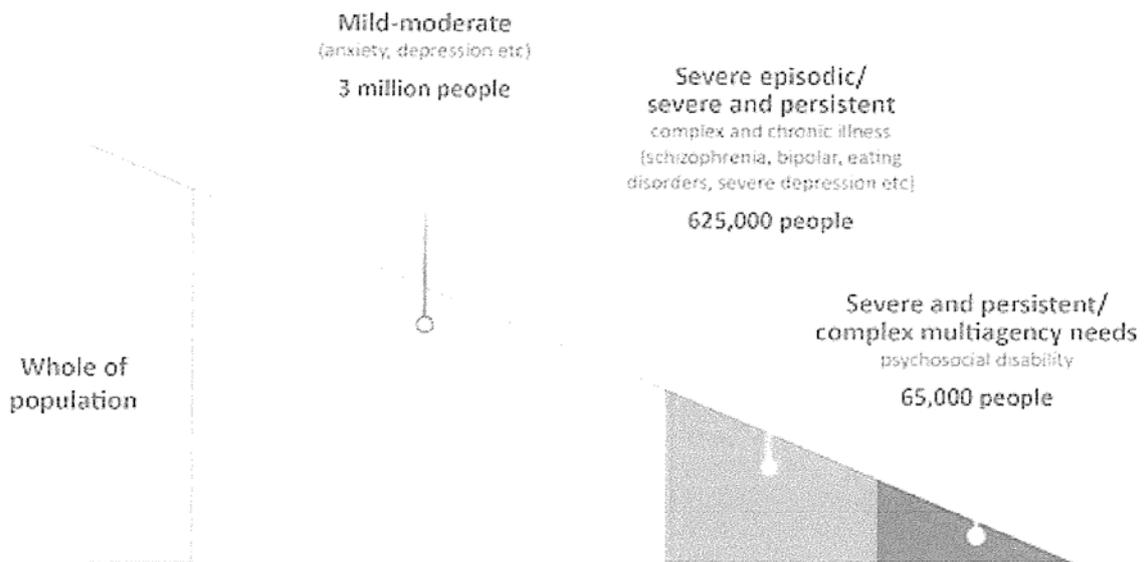
However, when it comes to attitudes and behaviour the story isn't as positive and here I make a further distinction between what Sane Australia[12] have labelled mild to moderate forms of the illness as opposed to those which are severe and episodic, severe and persistent and severe and persistent with complex multiagency needs. What they say about the numbers associated with the three parts of the spectrum is as follows, the total number affected being four million:

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[10] "Lessons learned from unintended consequences about erasing the stigma of mental illness", World Psychiatry, 15(1), 2016, p.69-70.
[11] Ibid, p.67.
[12] My thanks to Jack Heath for providing me with this table-and also his insights on stigma.

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Mild-moderate
(anxiety, depression etc)

3 million people

Severe episodic/
severe and persistent
complex and chronic illness
(schizophrenia, bipolar, eating
disorders, severe depression etc)

625,000 people

Severe and persistent/
complex multiagency needs
psychosocial disability

65,000 people

Whole of
population

Spectrum of mental ill-health in Australia

When it comes to mild-moderate illnesses, anxiety disorders and depression for example, we'd have to conclude there's been progress. All of us from time to time experience mental health problems and it's not a bridge too far for at least some of us to recognise that these problems can present as illnesses for which treatment is available. Awareness campaigns, personal story-telling and initiatives in the work-place and community have helped enormously in spreading knowledge about anxiety disorders and depression. What's important here too is a spread of knowledge about what can be done to successfully treat depressive illnesses.
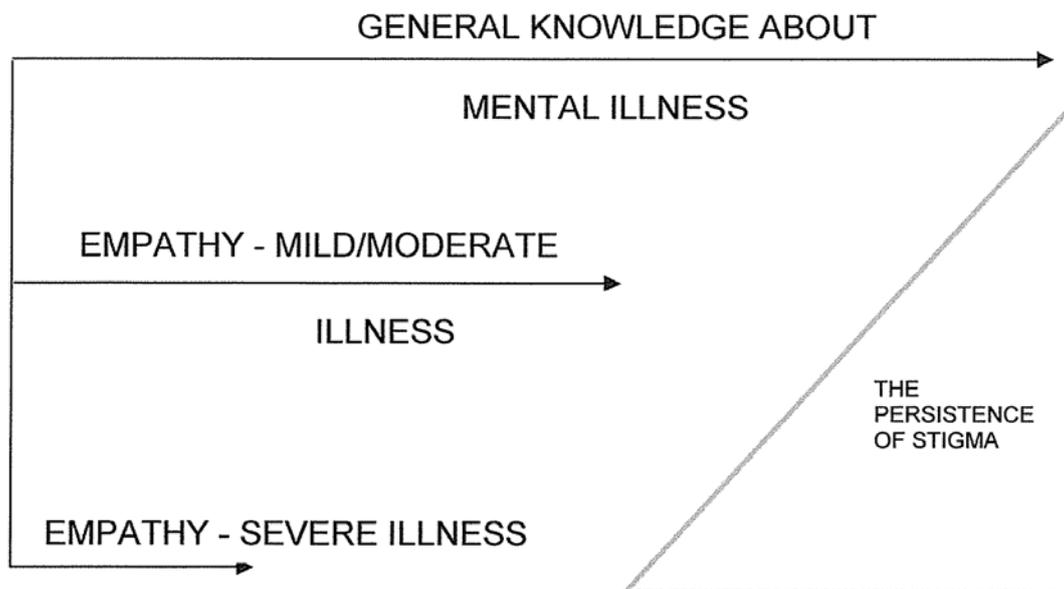
It needs to be said, however, that there's still a gap between our levels of knowledge and our commitment to counter the stigma attached to this knowledge. To put it crudely - we can know something but not have empathy about what its existence means. Two points are relevant here. Firstly, as noted before, the knowledge we gain that some people are different in the way they respond to the ups and downs of life may just feed into an "us" versus "them" narrative rather than a "you" and "me" solidarity narrative. That's why we now know that face-to-face interactions with people with mental illness are so important in building support, it being one thing to understand something at an intellectual level but quite another at an emotional level. Secondly of course, there's still the powerful social forces telling individuals that work and material welfare are all-important and should be accorded priority even when our minds - and perhaps our bodies too - are telling us that all is not well. Indeed, all too often feelings are bottled up and relief sought in ways damaging ways such as excessive alcohol and drug use.

However, this all being said about a degree of progress in respect the mild to moderate forms of illness, the matter of severe episodic and severe and persistent illnesses remains a more difficult challenge. Illnesses like schizophrenia, severe depression and anti-social personality disorder don't just challenge us intellectually and emotionally but also existentially. Writing in Australasian Psychiatry, Dusan Kecmanovic explains why this may be so:

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There are three key characteristics of people with mental illness that make them subject to stigmatisation: they are perceived as unreasonable, unintelligible and unpredictable. Persons who are perceived in that way cannot help but to be seen as dangerous, in our everyday social life we rely on reasonableness, intelligibility and predictability of people we, directly or indirectly, communicate with. If someone does not meet these basic requirements for mutual understanding and appropriate communication, he or she challenges our social existence, and thereby threatens us[13].

He goes on to note that "there are few things mentally sound persons abhor more than chaos - it reminds them of their own frailty, and the infirmity of the world". So, it is that "they tend to distance themselves from people with mental illness. They want them out of their sight, and out of their mind"[14]. Unlike those with depression or anxiety disorders who might be described as weak and incapable those with serious disorders are all too easily stereotyped with labels like "out of control" and "dangerous". After all some illnesses can have such consequences. Hospitalisation may be necessary, indeed in certain circumstances it may be mandated. Add to the equation the fact that a significant number of the prison population have depression, anxiety disorder or a personality disorder. Empathy may be needed but isn't always easy to get.

With these thoughts about the existential ("we need order") and social ("we need growth") factors involved with stigma I would define the situation as follows: Our knowledge base has improved as has our overall levels of empathy but not enough, particularly when it comes to serious illness. Stigma has been dented and diminished but not defeated.

GENERAL KNOWLEDGE ABOUT

MENTAL ILLNESS

EMPATHY - MILD/MODERATE

ILLNESS

THE
PERSISTENCE
OF STIGMA

EMPATHY - SEVERE ILLNESS

A RADICAL ALTERNATIVE - LAING AND SZASZ

Before resuming this story let me take a short detour back to the time when revolution was in the air and all things were being subject to critical examination, including our attitudes to mental illness. There was a view - significant at the time and not without its consequences - that the

[13] "The future of psychiatry", Australasian Psychiatry, 20(6), 2012, p.469.
[14] Ibid.

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mainstream approach I have adopted thus far, namely that there is such a thing as "mental illness" is bound to fail[15]. Thomas Szasz argued that mental illness was a "myth" and to define someone as such was in itself to stigmatise them. He railed against what he called "the therapeutic state" and its attempts to medicalise all things. Another radical, R.D. Laing, argued that the mentally ill were stigmatised because they were truth-tellers to a world not willing to listen. He once said mental illness was a "perfectly rational response to an insane world". Of those who say a person seriously ill with schizophrenia is incomprehensible he wrote:

> One may see his behaviour as 'signs' of a 'disease': one may see his behaviour as expressive of his existence.

Like Szasz but with a different framework he saw much that was medical treatment as unjust and dehumanising.

The common theme here was to liberate the mentally ill from a system that seeks to define, manage and control them and by so doing denying them of their personhood. Szasz and Laing reminded us in a powerful way that there are important human rights issues at stake and also that those with mental illness can't simply be abstracted from their social context[16]. We would have to conclude nevertheless that they provided reminders rather than practical solutions or, as Rachel Aviv wrote in The New Yorker when discussing the case of seriously ill people devoid of self-awareness in respect of their condition and its consequences: "Freedom often ends up looking a lot like abandonment"[17]. Over the years we've seen examples of this abandonment and much unnecessary suffering as a result.

EDUCATION AND CONTACT

This all being said we're left with the problem outlined earlier and that is despite a good deal of progress stigma still exists, feeding off the belief that the mentally ill are either weak (that is to say lacking in the will needed to tackle illness) or dangerous (that is to say captured by their condition and capable of harm to themselves and others). That there is a good deal of ignorance displayed by such views is clear but clear too are the understandably human realities that underpin both examples of stereotyping and stigmatising. Most people do experience the ups and downs of life but go on to recover. They find it hard to understand why others can't do the same. Most of us too are disturbed when confronted with behaviour that is, at best, confusing and, at worse, anti-social and sometimes violent.

Putting these factors into the mix helps explain why our campaigns against stigma aren't as effective as we'd like. This leads me to an important conclusion reached by Patrick Corrigan: "It is not the professional expert teaching facts of illness that changes stigma, but contact with people sharing stories of recovery"[18]. Indeed, in another paper of which Corrigan was a co-author it is written:

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[15] The quotes that follow are from Anthony Stadlen, "Thomas Szasz Obituary", Guardian, 4 October 2012 and Allan Beveridge, "R.D. Laing revisited", Psychiatric Bulletin, 22 (1998), pp. 452-456.
[16] For a comprehensive overview of the rights issue see Alan Rosen, Tully Rosen and Patrick McGorry, "The human rights of people with severe and persistent mental illness" in M.Dudley, F.Gale and D.Silove (eds), Mental Health and Human Rights (OUP, 2012), pp. 297-320.
[17] "God knows where I am. What should happen when patients reject their diagnosis?" New Yorker, 30 May 2011
[18] "Lessons learned", p.72.

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...research on educational campaigns suggests changes of behaviour are often not assessed, effect sizes are limited, and programmes are more effective for participants who have a better knowledge of mental illness before the education or had contact with persons with mental illness beforehand. Thus, educational programmes tend to reach those that already agree with the message[19].

They go onto say that "research has shown that members of the majority who have met minority group members are less likely to stigmatise against members of this minority'[20].

What all of this tells us is that the known prospects for recovery, in all of the senses we understand that concept, is important in the war against stigma. Recovery is a metaphor for progress and progress is a powerful force in our society. So too is hope, the hope that things can be better. It's only when the "us" and "them" frame of thinking isn't challenged by successful interventions that otherwise sympathetic people, including health professionals, are led to question whether or not what they are doing is worthwhile. If it's seen as "all too hard to change" then it won't change! We often see a similar thing playing out in respect of the way Aboriginal and Torres Strait Islanders are stereotyped for failure.

DEMONSTRATING PROGRESS

An important factor in tackling stigma, then, is progress in the treatment of illness itself, whatever form it takes. In saying this I draw your attention to a recently published article by Melbourne psychologist Nick Haslam. Writing in The Conversation[21] he refers to recently conducted global research which shows that from 1990 to 2011 "both psychiatrists and psychologists enjoyed steadily rising levels of confidence as treatment providers" and concludes that the public appears to have "a generally positive view" of health professionals and the "kinds of help they dispense". However, despite this confidence and the increasing rates of clinically-trialled treatments there have been no community wide improvements in mental health itself. Indeed, the average levels of psychiatric symptoms are either static or on a gentle upswing.

It could be the case, of course, that the causes of this are life becoming harder in these years or to reduce stigma leading to more disclosure. The researchers found little evidence to support the first thesis and in respect of the second conclude that it is "credible" but not as much as another explanation, namely that treatment is poorly implemented. Haslam calls it a "quality gap" and goes onto say:

> Too much mental health treatment is not evidence-based. Too much treatment does not target the right people, and too much is inadequately delivered.

We must, says Haslam, close this gap and ensure treatment is sound, in other words relevant to the individual and his or her circumstances. He also notes that "insufficient attention is paid to preventing mental health problems in the first place". Life may not have become tougher but that doesn't preclude a conclusion that our society is too accepting of policies and practices, be

[19] Rusch, Angermeyer and Corrigan, "Mental illness stigma", p.535
[20] Ibid.
[21] "Does more mental health treatment and less stigma produce better mental health?" The Conversation, 31 January 2017.

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they social, economic or environmental, which can contribute to, if not cause, mental problems and mental illness.

Expectations are one thing but results quite another and stigma is one of those issues where improvement in outcomes is needed for improvement in attitudes. There's no way around it, the causal factors have to be reversed and reasons given for being supportive rather than stigmatising. We need to show in practice what we say in theory. This takes us to all the decision-makers be they health professionals, public officials or politicians. They have a special responsibility to be up-to-date in their thinking and practice. For the health professionals that means recognising they are dealing with individuals all of whom will have their different histories and characteristics. For policy makers that means ensuring relevant services where and when required and support for laws and regulations to deal with discriminatory and/or dehumanising practices. What success in service provision and application provides is a context in which contact between the public and people in recovery can work its magic in undermining stigma.

CONCLUSIONS

What, then, can we conclude from the points I have addressed in this essay?

Firstly, it is a pre-condition for any attempt to de-stigmatise mental illness that mental health be part of our politically approved definition of progress. It's not just about GDP! However, it's not just a case of incorporating mental health into the definition of progress but to ensure it is the science of mental health about which we speak. We want the wise to be active and the active to be wise.

Secondly, it's important that when considering priorities, we note that the more serious the illness the more stigmatising is the community response. Not only do we want the active to be wise but to be more focussed on supporting those for whom the pains associated with stigma are particularly severe. More than any others they represent the "wounded man" left on the side of the road somewhere between Jerusalem and Jericho.

Thirdly, we've seen that a wide variety of education campaigns work best when part of a partnership, both direct and indirect, between the public and those who are ill and seeking recovery. So too do "professional voices of hope and self-determination behind a person's story of recovery, instead of gloomy prognosis that often colours   media images, exponentially advances anti-stigma goals".[22] In saying this the concept of solidarity comes to mind.

Fourthly, we need to acknowledge that stigma persists and, more likely than not, because there is insufficient evidence provided to the public and too many setbacks experienced by those who are ill, to justify a change of view. Such evidence can only come through a better performing system of care and a society more focussed on the social, economic and environmental factors conducive to ill-health. It's not just professional voices of hope we need but professional and community initiatives that deliver better outcomes, including in respect of access to work and housing as well as health care.

Doesn't that leave us with a catch-22? We need to combat stigma if more and better services are to be provided and accessed but at the same time we need more and better services if stigma is to be combatted and services accessed. The truth is we need both, anti-stigma campaigns and de-

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[22] "Lessons learned', p. 72.

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stigmatising service delivery. It's not just about how we think about mental illness but also about how we address the issues it raises; and we need the two to be working in concert. We need to do better in order to do even better. As Corrigan puts it so well: "The services message seeks to destigmatise mental illness by framing them as treatable conditions. The rights message poses mental illness stigma in the same light as any civil right, calling for ending discrimination and promoting opportunities"[23] . My only amendment to that formulation would be to say that the services agenda not just be seen as an exercise in "framing" but also as one of "doing and proving". We need those efforts to produce tangible results if we are to go further than we have thus far in convincing others that their prejudices are not only contrary to our views of right and wrong but also misguided in their estimation of what we can achieve through the power of enlightened endeavour. Compassion plus science is a powerful brew, let's be more serious about making it a day- to-day habit rather an optional extra!

[23] "Lessons learned", p.70.

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