

REMOVING THE STIGMA - ISSUES & OPPORTUNITES

By Leanne Pethick

In July last year I wrote an article for the depressionNet newsletter about what we can all do to help to reduce the stigma that exists surrounding depression. This article [Removing the Stigma](#) spoke of how we, people with depression, hold the key to reducing the stigma that surrounds depression and mental illness. "We have the illness, we understand it, and when we can say this without shame a real change in the community will happen so much faster." This month's article looks at a specific segment within the community – mental health organisations and the power they have to help us all move forward to reduce the stigma within the community.

Recently I felt insulted by being labelled a 'consumer'. As someone with a deep desire to play an active part in removing the stigma surrounding depression, I was disappointed and confused by my reaction. I am very comfortable with it stating clearly on the Internet that I experienced major depression in 97/98. When asked how I came to be involved with depressionNet I feel no emotion either positive or negative in replying "my personal experience with depression". Given that my formal qualifications are in Mathematics (not generally related to mental health! ☺) I am asked this question frequently both in my private life and publicly. It is just not an issue for me. I have been called a consumer in other situations and barely noticed, certainly I was not insulted. I had believed that I had personally left the negative impact of the stigma surrounding depression far behind. I was wrong.

So why did I feel insulted now? Why was one of the first questions that came to mind, "What the hell is a consumer?" Why did it matter what the term consumer specifically referred to? Finally, after many hours of soul-searching, of investigating possibilities, came the answer. *Because I know it matters to the people who applied it.*

The fact is that any label applied by someone who would be ashamed or embarrassed, who would not be willing and comfortable to wear that label themselves, will be taken as an insult.

While this particular report was from the CMHR and BeyondBlue, the challenges and issues this example highlights are not restricted to these organisations. This experience and many hours of investigation and analysis since, has highlighted some major issues that exist within the mental health industry that need to be immediately addressed if there is any hope of de-stigmatising mental illness.

With 1 in 5 people in Australia experiencing depression at some time in their lives, the probability of any random group of 20 people not including someone who has, or has had depression is extremely low. An organisation whose purpose is to do something positive in the area of depression or mental health, if anything, would tend to attract people who have experienced depression first hand and have a personal desire to contribute.

Why then do organisations such as BeyondBlue need to have a separate 'consumer representative'? Is there no one within the organisation already who could fill that role? It is far more likely that there is no one within the organisation that wants to fill this role than it is that there is no 'consumer' (given the current use of the word) within the organisation. The BluePages website produced by the CMHR gives an extensive list of occupations and expertise on their 'Advisory Team', yet states that 'consumers were consulted anonymously'.

Why is it that organisations such as the CMHR and BeyondBlue and 22 other major organisations we checked in the mental health industry don't have anyone on their teams or on their editorial boards, advisory teams etc, who are healthcare professionals or fill any other role within the organisation and who have had depression?

If we look just at healthcare professionals, there were nearly 100 included in those organisations we investigated and there was not one person who also held the role of 'consumer'. There are psychiatrists who were CEOs, Chairs, even site developers, but there was no psychiatrist who was a consumer. Similarly for all health care professions. Yet consumer is a term that is applied to someone who has had depression and it is these organisations that are telling us that depression is so common.

Could it be that they fear that if they disclose that they have even had depression in the past, one day a report may be published that says "Jo Smith, a consumer", and forget to mention that Jo Smith is also a qualified psychiatrist, that Jo Smith has extensive experience in fields relevant to the report, that he took his own excellent advice and may have recovered or at least have no symptoms of depression, in fact dismiss anything else about Jo Smith and hold the fact that Jo Smith has depression as the most important thing to report about Jo Smith? This is exactly what happened in the report that I found insulting.

The appendix to the report *The quality and accessibility of Australian depression sites on the World Wide Web* gives a very brief 'description' of Australian depression sites and states "... Leanne Pethick, a consumer." Is the most relevant, important or impressive thing about Leanne Pethick the fact that I don't hide the fact that I have had depression? The 'about us' section of the depressionNet site clearly gives my current occupation, my formal qualifications, relevant experience and other information that may be relevant. Yet the most important piece of information the researchers chose to include about the site founder and owner in a description of depressionNet is 'a consumer'.

Now the report states that 'ownership structure' was one of the elements included in the assessment of quality. What the report didn't give, was any indication of how this element was rated. Does ownership by a 'consumer' earn a high or low rating? What level of rating of quality does ownership by a 'psychiatrist' – as given for another website – receive? What quality rating does a website owned by an organisation such as BeyondBlue, with both consumers and psychiatrists on its board receive?

Given that 'consumer' becomes the most important piece of information where website ownership is concerned, overriding qualifications and relevant experience, I can well understand why a psychiatrist would not be comfortable with letting anyone know they have, or have had depression in the past. Actually, I can understand why no one would want to reveal they have had depression! I certainly no longer believe I am over reacting for having felt insulted.

The fact is that healthcare professionals are human beings the same as any other segment of the population, and are themselves victims of the stigma surrounding depression.

There is no doubt that the term consumer is currently used within the mental health industry to identify very different segments without clearly defining the segment under discussion and at times includes or extends to segments of people who do not use any mental health product or service. As such the common use of the word is incorrect and confusing.

Whenever I have asked "What is a 'consumer'?" within the mental health arena I have not actually received a direct response, only a discussion on 'what other word we can use?' No one has actually provided a definition. The point is we should never use a word we can't define, particularly as a label for another human being.

Clarification of the meaning of 'consumer' wherever it is used in mental health and thoughtful and responsible use of the word by all is an essential element in preventing responsible and caring people and organisations from inadvertently promoting the stigma we all wish to eliminate. If we want to have a positive impact on reducing the stigma, if we want to avoid inadvertently insulting people, we need to immediately stop using the word 'consumer' both in general and when applied as a label to an individual, unless we and the reader know what that term means.

One of the most commonly espoused strategies for reducing the stigma is to educate the community and increase awareness of the prevalence of depression. Organisations such as the CMHR and BeyondBlue would know as much about the clinical aspects of depression and the prevalence of depression as anyone. Yet the stigma surrounding depression is alive and well within these organisations. Obviously awareness and education is not enough.

To really have an impact on the stigma, what we need is for people to lead the way, for those who are best positioned to know that there is nothing to be ashamed of to be comfortable letting us know they have or have had depression. As leaders in the mental health industry, as experts and educators in all clinical aspects and awareness, healthcare professionals within mental health organisations are in the

best position to have the most powerful, immediate, positive influence on the stigma associated with having, or having had depression.

You are telling us that depression is treatable and manageable, that when properly treated it does not have to be disabling. Yet communication is more than verbal and written – actions speak louder than words. Your silence, your need to have 'consumer representatives', your need to 'consult consumers anonymously', communicates more than your words.

The stigma both within the community and within myself prevented me from seeking professional help until my depression was so bad I had no choice. I experienced the horror of a major depressive episode and felt first hand the impact of the stigma I held towards depression.

I believed you when you told me how common depression is. I believed you when you told me that having depression was nothing to be ashamed of. I braved the stigma to be open about having depression and in doing so discovered hundreds of other people like me in my own world and overcame the stigma I held towards having depression myself. Do you believe what you say?

To really reduce the stigma within the community at large, we need you to do more than hold up a token actor, more than consult an 'anonymous consumer'. We need you to show us that there is nothing to be ashamed of. We need the people who are 'talking the talk' to 'walk the walk'.

We, all Australians living with depression, need you to lead the way and show by example that there is no need to be ashamed of having had depression.

By identifying that the current use of the word 'consumer' perpetuates the stigma and how it does this, we also identify an exciting opportunity to move forward.

All mental health organisations and the people and organisations who accept roles as educators or provide information about depression and related conditions can accept responsibility for communicating clear and accurate messages and information and make immediate changes to do so. We can then identify areas where we can make an immediate difference and lead the way and show by example that no one needs to feel ashamed or embarrassed for having or having had depression.

depressioNet is created for and by 'people like us' – Australians living with depression. This includes health care professionals both on the depressioNet team and as visitors. We have no need to use the word 'consumer' and don't. There is no shame in having depression at depressioNet regardless of occupation, qualification, age, gender or any other issue. I invite all who genuinely wish to reduce the stigma surrounding depression to walk with us.

"There is no shame in having a psychiatric condition or caring for another person who has one. Take away shame and anything's possible." - Neugeboren

"We will repent in this generation not so much for the evil acts of the wicked people, but for the appalling silence of the good people." - Martin Luther King