depressioNet Submission to the Senate Select Committee on Mental Health

June 2005

Prepared By: Leanne Pethick
CEO, depressioNet

depressioNet.com.au

The purpose of depressioNet is to empower people to make informed choices and find solutions to the challenges of living with depression.

Background

The Australian Government is looking for innovative, cost effective initiatives that provide solutions to health issues within the community, by the community, and reach the maximum number of people with minimum infrastructure. 'depressioNet' does this, and has done so successfully since June 2000.

Initially a privately owned philanthropic project, in 2003 depressioNet became an Income Tax Exempt Charity operating as an independent NGO with a suitable Board and Governance structure.

depressioNet.com.au was the most visited Australian health website within 4 months from conception with no promotion or advertising. This is an extremely powerful testimony to need for the depressioNet model of peer based information, help and 24-hour support.

Provided by and for people living with depression, depressioNet is a unique model of true empowerment. Rather than 'us' empowering 'them', depressioNet provides a safe and secure environment for the 24 hour information, help and peer support that is essential for people living with depression to work together to validate, support and encourage each other to make informed choices and find solutions to the challenges of living with depression.

The role of depressioNet is not to complain about the way the world is (organisations such as beyondblue are more appropriate to take complaints to in the hope that they may be able to effect change in the quality and quantity of professional help etc), but to work together to say 'What *can* we do?'

Introduction

Through the direct interaction, facilitation and 'service delivery' provided by depressioNet to many thousands of Australians living with depression and related conditions over the past 5 years, we have a wealth of knowledge and importantly a new and clear community based perspective on many of the challenges facing people living with depression and other mental illnesses.

Unfortunately the ridiculously limited resources at depressioNet have made it impossible for us to find the time to prepare a submission of the quality and calibre of which we can be proud and that will do justice to the potential value we may bring to this Inquiry.

depressioNet focuses on the needs of the individual living with depression and related conditions as our first priority in all that we do. The Team here have all been working 7 days a week to maintain the vital depressioNet 24 hour services and finding the support needed to keep depressioNet here in the future.

We ask that the Senate Select Committee for Mental Health accepts this brief paper as an important voice that is under represented in the submissions – that of people who live with depression. The issues we raise here are new, reflecting the lack of input received from people living with depression into mental health strategies and service provision in the past.

Finally, we ask that we be given the opportunity to present to the Committee. A formal presentation will enable us to provide more in depth explanations of the issues raised here and give members of the Committee the opportunity to ask questions and better understand the often subtle but significant impacts of these issues.

Summary

With depression, the most common mental illness and the WHO predictions that it will be second only to heart disease in prevalence by the year 2020, there is an urgent need to look objectively at:

1. the terminology being used within mental health
2. the current model /practice within the mental health industry of segmenting participants into the discrete categories of 'Mental Health Professionals, Carers and Consumers'
3. why 'mental health' in general is considered separately from physical health, and if the reasons are no longer valid, no longer doing so.

It is not acceptable to continue using models and terminology without thinking or because that is the 'norm' or 'that is the way it is done' within mental health. The vast majority of the population do not have any direct interaction with the 'mental health industry' and hence have no awareness of the subtle but powerful differences in meaning behind words and terminology as is currently commonly in use within this sector.

By embracing change in these areas, significant steps forward will be made with benefits including but not limited to:

1. Reduce the stigma associated with a number of different mental illnesses;
2. Improve the accuracy of information and communication at all levels;
3. Improve the quality of services provided to a broad range of people;
4. Increase access to professional help and treatment for depression;
5. Encourage more people from a wide variety of backgrounds and segments within the community to actively participate in and contribute to the health and wellbeing of all Australians.

It is very often the most subtle things that are the most powerful, and this is particularly true where communication is concerned.

There exists an exciting opportunity to implement changes in the above areas that will have a significant positive impact on the health and well being of all Australians and in particular, people living with depression.

ISSUE 1: Communication = Terminology and Language

There are many terms and phrases that are in common use within the mental health industry in Australia and used when communicating with the media and broader public that are not clearly defined, may be misinterpreted because their meaning in the general community is different from that assumed within mental health, and/or inadvertently negatively impact people and segments as well as sabotage attempts at destigmatisation. Throughout this document and in this section in particular, we look at some examples.

Depression is an illness that affects all Australians. With 1 in 5 people experiencing major depression at some time in their lives, and most people experiencing mild to moderate depression, all Australians will either have depression or have someone close to them who does. Some people fully recover from an episode of major depression. Some people with depression have a chronic condition that requires ongoing management. depressioNet has always used the term 'people living with depression' to refer to the segment it was created to serve – all Australians living with depression.

Example 1

Currently it is common practice to refer to people who have depression as 'depression sufferers'. However there are many thousands of Australians who have sought treatment for depression and whom currently still have chronic depression but who have this condition effectively managed so that they do not 'suffer' any of the symptoms. This is what we want to encourage all people with depression to aim for and act upon. Ideally no person will 'suffer' from depression for more than a few months at most, and as people start seeking treatment earlier, most need 'suffer' the symptoms for even shorter timeframes.

It is essential that people living with depression effectively managed are not referred to as 'depression sufferers' if we want to encourage people to seek help and destigmatise depression. The term 'depression sufferer' must only be used when specifically referring to those people who are suffering the symptoms of depression.

"Depression sufferers" and "People living with depression effectively managed" are both sub-segments of the broader group of 'People living with depression'.

Example 2

We commonly hear it stated – and by depression experts – that 'depression is one of the most disabling conditions'.

It is widely publicised that depression is one of the most disabling illnesses in Australia today. However this statement is at best incomplete and misleading and most importantly, contributes towards the stigma for people with a treatable illness. It is not surprising that people in the workforce don't feel comfortable saying that they have depression!

The truth is that *untreated* depression is disabling. Correctly treated and managed and with appropriate support structures and strategies, over 85% of people with depression can be symptom free within 10 weeks[1].

Effectively treated and managed there is a high probability that a person living with depression may experience no disability at all. This is what we need to be communicating clearly and consistently.

[1] Professor Martin Keller 2002

The current use of the term 'mental health consumer', often abbreviated to simply 'consumer', may have been appropriate in the past. It has enabled people who were largely disempowered to have an important voice in mental health service provision and empowered them to drive some positive changes in government policy, service provision and the mental health industry in general.

However the term mental health consumer or 'consumer' in mental health is rarely assigned a clear meaning, is often used inappropriately and when referring to very different segments. The use of these terms is confusing and contributes to incorrect or misleading information, significant misunderstanding and even inadvertently increasing stigma.

The current 'consumer' voice in Mental Health is that of consumers of mental health services (MHCs). This consumer voice advocates for people with long term chronic disabling mental illnesses and focuses on their needs such as improving mental health services, 'integrating consumers back into active participation within society', etc. It represents less that 10% of people living with depression.

As most people living with depression (PLWD) do not self identify, or seek treatment, their needs and issues are generally not incorporated into program development. Current programs have the input of HealthCare professionals, Carers and MHCs, hence represent the needs of these groups, but claim to represent the needs and issues of all Australians living with mental illnesses – including people living with depression.

Example 3

The 'Depression and the Community' supplement of the MJA in May 2002[2] contained an article titled 'Responding to the Australian experience of depression: the view of the Mental Health Council of Australia "

This article does not in fact reflect or give any information about the 'Australian experience of depression'. Rather the issues it cites and discusses are issues for consumers of mental health services. Certainly at the time it was written, the position of the Mental Health Council of Australia (MHCA) was that the majority of people with depression were not seeking any professional help, much less using mental health services or wanting to actively participate in mental health service provision.

Note: See also Supporting Document "MHI – MHCs & PLWD 2002.ppt". Due to insufficient resources, depressioNet has not yet had the opportunity to implement the stigma reduction strategy referred to in this document.

Example 4:

The need to differentiate between mental illnesses in order to address the needs of individual segments properly and the current lack of understanding around this has had a significant negative impact on depressioNet's ability to meet the needs of the segment it was created to serve – people living with depression.

The needs for peer support for people living with depression and the peer support needs for people with other mental illnesses are not only very different, but at times directly conflicting. This is explained in more detail in Appendix 3.

[2] The Medical Journal of Australia 2002; 176 (10 Suppl): S57-S104
http://www.mja.com.au/public/issues/176_10_200502/depression.html

ISSUE 2: Mental Health Industry Model

The current practice of segmenting those involved in mental health into 'professionals', 'carers' and 'consumers' has significant negative consequences. Where does a professional person working full time with major depression and with full 'caring' responsibility for two young children 'fit' in this model?

No professional person is going to identify that they have depression – a mental illness – as they are immediately labelled a 'consumer' regardless of qualification or experience. depressioNet receives a very large number of requests to help find professional treatment and support services *outside* their local area from people who work in mental health.

Example 5

The 'Depression and the Community' supplement of the MJA[3] also contained an article 'The quality and accessibility of Australian depression sites on the World Wide Web '

This article gave the results of research conducted by the Centre for Mental Health Research at the Australian National University. 10 websites were profiled and names, qualifications and/or occupations of individuals associated with many of these were given, for example 'Peter Smith, psychiatrist'.

Leanne Pethick was the only person named who had any previous professional experience in managing a quality website and although this professional person had relevant qualifications and experience in high level website management, they were referred to as 'Leanne Pethick, a consumer'.

Why? Because the authors of the article were aware that this person had suffered major depression a number of years earlier and in this strange world of the 'mental health industry' having had depression becomes the most important quality, stripping away relevant experience, qualifications, personal and professional contribution, quality of output, or any other usual means of assessment of suitability for a role.

Is 'consumer' a qualification or an occupation? What relevance in the world today does having had depression have in providing a quality and accessible depression website?

Within the mental health industry today, the term 'professional' is taken to mean mental health professional. There is no recognition of, or room for, any other professional. In truth, historically no other professional would want to be involved in mental health. As we achieve our aims of destigmatising depression, this must change if we want to encourage and engage all members of the community in improving (mental) health and well being.

Note: This example was the subject of the depressioNet Newsletter article in May 2002 which is included in the supporting documentation.

Example 6

To take an extreme example, the CEO of a multinational corporation seeking to become engaged and contribute to reducing the impact of depression within the community, would not feel 'at home' in attending a Mental Health Consumer conference. They would not find people with similar issues and challenges.

They may however feel that they were amongst their peers when attending a conference for 'People Living with Depression'. It is a part of the vision of depressioNet representing people like us, all Australians living with depression, to be able to one day host such a conference. While health professionals may attend, it is not their professional qualification but whether or not they live with depression that will attract them – as for all.

---

[3] The Medical Journal of Australia 2002; 176 (10 Suppl): S57-S104
http://www.mja.com.au/public/issues/176_10_200502/depression.html

ISSUE 3: Health = Physical and Mental

It is rare to hear anyone refer to 'the issues for people with a physical illness' because people with different physical illnesses have different issues. The issues for people with the common cold are different from the issues for people with aids, are different from the issues for people with muscular atrophy.

It is just as inappropriate to refer to 'the issues for people with a mental illness'.
The issues for people with depression are very different from the issues for people with schizophrenia, are different from the issues for people with post traumatic stress disorder.

The current practice of 'bundling' all mental illnesses together and using the term 'mental illness' when referring to issues which are relevant only to people with one or some mental illnesses (and particularly not relevant to other mental illnesses) is inappropriate and a major barrier to achieving desirable outcomes for any segment of the population.

Why is the word 'mental' used far more often than 'physical'? For example:
There are 'health consumers' and 'mental health consumers' but no 'physical health consumers'. There are 'health associations' and 'mental health associations', but no 'physical health associations.' Why?
In physical health, the particular condition or illness is identified and the needs and issues of people with that illness addressed.

Physical health practitioners no longer consider the physical health of their patients to be independent of their mental health. It is now generally accepted that the mental health of a person has a significant impact on physical health outcomes.

Many physical illnesses are 'comorbid' as are many mental illnesses. Physical and mental illnesses are often 'comorbid'. It is common for people with schizophrenia to also have depression. Recent research has also shown that people with heart disease are more likely to have depression as well. The list of common comorbid conditions (physical and/or mental) is enormous.

We do not say that someone has a 'physical illness' and it is now well and truly time for this approach to expand and include all areas of human health. It is time to stop saying that someone has a 'mental illness'. If we have an illness, then identify what illness we have. If we have a secondary condition that needs treating, let's also identify that.

The term 'mental health' should only be applied in the same situations that the term 'physical health' would also be used and deemed essential to differentiate from 'mental health' or 'spiritual health' etc. In fact if we use common practices in physical health as a guide when communicating about all health and specifically when referring to mental health, significant steps forward will be made.

Examples:
'Health consumer' organisations include people with physical and/or mental illnesses.

Organisations established for, providing support or a service to, (etc) people with a specific condition or illness, state the particular illness or condition.

Where we are talking about the issues for people with health problems – this encompasses both physical and mental health problems / illnesses.

When we are talking about the issues for people with specific conditions, the specific condition and segment is named and referred to.

Example a: Cancer patients, people with cancer, people at high risk of developing cancer.
Example b: People with PTSD, PTSD patients, people at high risk of developing PTSD.

Example 7: Stigma

In particular, **it is impossible to address the stigma of mental illness** without clearly defining which mental illness is being referred to and describing the issues and impacts of that mental illness and the manner and effect of the 'stigma'.

To consider the 'stigma of mental illness' is the equivalent of considering the stigma of physical illness, which begs the question "Which illness?"

There are many different mental illnesses of varying degrees of impact and disability with significant differences in treatment durations and expectations regarding ability to live with the illness effectively managed so that the individual is 'a-symptomatic'.

Put very simply, a person with severe, 'treatment resistant' depression / anxiety, schizophrenia, personality disorder, etc often experience significant ongoing disability that negatively impacts their ability to work. Stigma for this person is being seen to be a 'malingerer' because they are not working full time.

For someone with depression – a mental illness – which is effectively treated and managed and whom has not experienced any symptoms for a number of years, the stigma is being seen to be less able or competent in the workplace.

In fact the stigma for a person with schizophrenia has more in common with the stigma of some physical illnesses than it does with the issues around stigma for most people living with depression.

Note: While many of the examples given in this submission refer to articles from 3 years ago, this is because it was over 3 years ago that depressioNet identified these challenges. The issues expressed here are just as relevant today – if not more so. We could equally use examples from today. In fact in taking a random sample of the submissions to the Committee, all submissions prepared by people and organisations from within the mental health industry contained numerous relevant examples of these issues.

Response to the Terms of Reference

The Select Committee on Mental Health has been appointed to inquire into and report on the provision of mental health services in Australia, with particular reference to sixteen issues as given in the 'Terms of Reference' (Appendix 1).

The issues discussed earlier in this report form the foundation of the depressioNet response to the Terms of Reference. It is important to note that as a result of these issues, many of the Terms or Reference are irrelevant to the vast majority of people with a mental illness - people living with depression.

The following provides our specific responses to the Terms of Reference:

Terms of Reference a):

the extent to which the National Mental Health Strategy, the resources committed to it and the division of responsibility for policy and funding between all levels of government have achieved its aims and objectives, and the barriers to progress

depressioNet Response:

The Australian Government Department of Health & Ageing website provides a summary of "What is the National Mental Health Strategy" at http://www7.health.gov.au/hsdd/mentalhe/mhinfo/nmhs/whatis.htm and states:

"The Strategy is a commitment by State, Territory and Commonwealth governments to improve the lives of people with a mental illness. It ***provides a blueprint for the future delivery of mental health services in Australia***.

The aims of the National Mental Health Strategy are to:

- promote the mental health of the Australian community;
- where possible prevent the development of mental health problems and mental disorders;
- reduce the impact of mental disorders on individuals, families and the community; and
- assure the rights of people with mental disorders.

Two major trends in mental health policy and service delivery have influenced development of the Strategy.

Firstly, efforts have been made to combine mental health services within general health services.

It is argued that wherever possible, people suffering from a mental illness should be treated in the same way as people suffering from any other illness. As a result, general hospitals, rather than specialised psychiatric facilities, should provide acute care for people suffering from a mental illness.

Treating mental illness within the general health system or within the community may also reduce the stigma associated with psychiatric treatment.

Secondly, if community-based care is to be effective, governments must provide an integrated network of different services. The National Mental Health Strategy outlines objectives and strategies promoting a community-based system of treatment and support.

The National Mental Health Strategy was developed with the needs of consumers of mental health services as its primary focus. While the aims can be taken to include all people in the Australian community, the 'two major trends in mental health policy and service delivery' that 'influenced the development of the Strategy' as given below, are obviously aimed at improving outcomes for consumers of mental health services.

While issues for MHCs are specifically addressed here, eg "…general hospitals, rather than specialised psychiatric facilities, should provide acute care for people suffering from a mental illness." the issues for people living with depression are not specifically addressed.

At best, the NMHS is incomplete due to its failure to clearly identify and address the needs of different segments of people living with a mental illness and as such, it is not surprising that it has not achieved its aims and objectives for the majority of Australians.

In specifically investigating the role of primary health care (Terms of Reference item g), we are assuming that the Committee does not view primary health care as a mental health service. The vast majority of the population would agree. Thus in 'providing a blueprint for the provision of mental health services in Australia', the National Mental Health Strategy is irrelevant for the vast majority of people living with a mental illness (depression) who will never use a mental health service.

With regards to 'funding', the fact that the federal government has handed control of funding made available to address issues specifically relating to depression to one 'independent' organisation is a major barrier to progress in general for people living with depression, and to the encouragement of innovative community based depression initiatives in particular.

Terms of Reference b) –e) inclusive:

See Appendix 1

depressioNet Response:

These are issues raised by and pertaining to people with other mental illnesses who are consumers of mental health services. While d) may be considered where depression is concerned, as above, the government has given control of all funding to one non-government organisation which is not necessarily responsible or 'appropriate'.

Terms of Reference f):

the special needs of groups such as children, adolescents, the aged, Indigenous Australians, the socially and geographically isolated and of people with complex and co-morbid conditions and drug and alcohol dependence

depressioNet Response:

No response at this time.

Terms of Reference g) & h):

g) the role and adequacy of training and support for primary carers in the treatment, recovery and support of people with a mental illness

h) the role of primary health care in promotion, prevention, early detection and chronic care management

depressioNet Response:

Absolutely critical for people living with depression. For the vast majority of people with depression, (and hence the vast majority of people with a mental illness) our GP is the only healthcare professional we will look to for treatment and support for depression.

Terms of Reference i):

opportunities for reducing the effects of iatrogenesis and promoting recovery-focussed care through consumer involvement, peer support and education of the mental health workforce, and for services to be consumer-operated

depressioNet Response:

While this item is specifically focussed on the issues for long term consumers of mental health services (MHCs), with the exception of 'eduction of the mental health workforce' this can be made relevant for people living with depression.

Thus we will respond here to "Opportunities for reducing the impact of depression on the lives of Australians and promoting mental health and wellbeing through community involvement, peer support and for services to be operated by people from within the community with a broad range of skills and experience including professionals who may be, but are not necessarily, also Health professionals."

depressioNet is a shining example of the opportunities for reducing the impact of depression on the lives of Australians through the provision of a professionally operated service providing 24-hour information, help and peer support via e-technology (website, online communication forums, email, etc)

Specifically depressioNet is a community founded, operated and run Not For Profit organisation that effectively:

- Reduces the stigma people with depression feel towards having depression themselves and empowering them to then reduce the stigma of depression within their families, workplaces and communities;
- Increases the proportion of people who seek professional help and treatment for depression;
- Increases the efficiency of professional help and treatment by meeting those human needs that are best met through peer support and hence reducing the need for General Practitioners (and other healthcare professionals) to provide understanding, validation etc. Thus people arrive more prepared to actively engage in treatment and benefit from the professional expertise of the healthcare professional;
- Increase understanding of treatment options;
- Increase adherence to treatment;

- Reduce the incidence of relapse;
- Improve mental health and well being.

In spite of the success of depressioNet in reducing the impact of depression on the lives of Australians[4] and the overwhelming support of people living with depression, practicing health and mental health professionals and the community, as an independent community based initiative created outside of the formal 'mental health industry' depressioNet received no practical support from either government or Mental Health Industry bodies in its first few difficult years and little since.

It has been the experience of all involved in depressioNet (including professionals from a broad range of related and non-related fields) that while the government purports to support and encourage community based initiatives, the reality is very different.

Terms of Reference j) & k):

j) the overrepresentation of people with a mental illness in the criminal justice system and in detention, the extent to which these environments give rise to mental illness, the adequacy of legislation and processes in protecting their human rights and the use of diversion programs for such people

h) the practice of detention and seclusion within mental health facilities and the extent to which it is compatible with human rights instruments, humane treatment and care standards, and proven practice in promoting engagement and minimizing treatment refusal and coercion

depressioNet Response:

Neither j) or k) are relevant to people living with depression.

Terms of Reference l):

j) the adequacy of education in de-stigmatising mental illness and disorders and in providing support service information to people affected by mental illness and their families and carers

depressioNet Response:

The current practice of using the generic term 'mental illness' rather than specifically addressing the issues contributing to stigma for different mental illnesses is a major barrier to destigmatisation of ANY mental illness. As such, current education programs are totally inappropriate and inadequate in de-stigmatising mental illness and disorders.

Similarly, eduction designed to provide support service information to people affected by mental illness and their families and carers (where appropriate) needs to be specifically targeted to the relevant segments of people with various mental illnesses. The level of specificity will significantly impact the effectiveness of any such education.

Terms of Reference m):

m) the proficiency and accountability of agencies, such as housing, employment, law enforcement and general health services, in dealing appropriately with people affected by mental illness

depressioNet Response:

What is 'appropriate' will depend on which segment of people affected by mental illness being referred to. The 'proficiency and accountability' of agencies in dealing appropriately with people affected by depression varies depending on the agency.

Currently when speaking of what is 'dealing appropriately' with people affected by mental illness, these agencies are focusing on the needs of MHCs. We have a number of rather extraordinary examples of the impact of this on people living with depression.

[4] See Supporting Document 'dNet User Survey Report Summary 050614

One of these involved a business woman who had walked into the emergency department of an interstate hospital to obtain a script for the antidepressant medication that enabled her to live with the symptoms of depressioNet effectively managed. She had left home without her medication and as it was after hours, the taxi driver suggested the hospital not far from her hotel.

When the woman entered the hospital she was healthy and well. Two hours later she was an emotional mess after having been in fear of being detained as she was 'obviously manic' and 'possibly psychotic'. The woman had never experienced a manic episode but was a friendly, confident and outgoing person. The attending staff treated her in what she considered a very rude and degrading manner.

It was explained to her that her behaviour was not consistent with a depressed person (she was not depressed) but someone who was manic. They had found her behaviour (responses to questions such as 'do you think you have special powers) paranoid and consistent with someone who was mentally unwell.

While this made an amusing tale after the fact, it was a frightening experience at the time with media stories of people being 'wrongfully detained' coming to mind.

The staff of the emergency department were only used to psychiatric patients with behavioural symptoms and saw what they were looking for. Emergency departments are not safe and supportive environments for people with depression.

Terms of Reference n) and o):

n) the current state of mental health research, the adequacy of its funding and the extent to which best practice is disseminated

o) the adequacy of data collection, outcome measures and quality control for monitoring and evaluating mental health services at all levels of government and opportunities to link funding with compliance with national standards

depressioNet Response:

Mental health research, data collection, evaluation etc are all heavily impacted by the current practice of using the terms 'mental illness' and depression interchangeably. Most importantly it is a barrier to the clear communication and understanding of the results of the research, how it is used and to whom it is applied.

Terms of Reference p):

p) the potential for new modes of delivery of mental health care, including e-technology

depressioNet Response:

There is enormous potential for new modes of delivery of mental health care from those mental illnesses with the most severe and long term symptoms for which there is no currently effective treatment which can achieve an absence of symptoms through to improving the mental health and wellbeing of people with no clinical mental illness.

For new modes of delivery to be effective, it is absolutely essential that practices applied in physical health are applied to mental health and that the final frontiers between the two are crossed.

depressioNet is also looking forward to having the opportunity to obtain a strong evidence base for the efficacy of online peer support in improving (mental) health outcomes for a number of segments through our 3 year 'dNet Centres Model' strategy soon to be implemented.

Appendix 1

Revised Terms of Reference for a Senate Mental Health Inquiry

(1) That a select committee, to be known as the Select Committee on Mental Health, be appointed to inquire into and report by 6 October 2005 on the provision of mental health services in Australia, with particular reference to:

a. the extent to which the National Mental Health Strategy, the resources committed to it and the division of responsibility for policy and funding between all levels of government have achieved its aims and objectives, and the barriers to progress

b. the adequacy of various modes of care for people with a mental illness; in particular prevention, early intervention, acute care, community care, after hours crisis services and respite care

c. opportunities for improving co-ordination and delivery of funding and services at all levels of government to ensure appropriate and comprehensive care is provided throughout the episode of care

d. the appropriate role of the private and non-government sectors

e. the extent to which unmet need in supported accommodation, employment, family and social support services, is a barrier to better mental health outcomes

f. the special needs of groups such as children, adolescents, the aged, Indigenous Australians, the socially and geographically isolated and of people with complex and co-morbid conditions and drug and alcohol dependence

g. the role and adequacy of training and support for primary carers in the treatment, recovery and support of people with a mental illness

h. the role of primary health care in promotion, prevention, early detection and chronic care management

i. opportunities for reducing the effects of iatrogenesis and promoting recovery-focussed care through consumer involvement, peer support and education of the mental health workforce, and for services to be consumer-operated

j. the overrepresentation of people with a mental illness in the criminal justice system and in detention, the extent to which these environments give rise to mental illness, the adequacy of legislation and processes in protecting their human rights and the use of diversion programs for such people

k. the practice of detention and seclusion within mental health facilities and the extent to which it is compatible with human rights instruments, humane treatment and care standards, and proven practice in promoting engagement and minimizing treatment refusal and coercion.

l. the adequacy of education in de-stigmatising mental illness and disorders and in providing support service information to people affected by mental illness and their families and carers.

m. the proficiency and accountability of agencies, such as housing, employment, law enforcement and general health services, in dealing appropriately with people affected by mental illness

n. the current state of mental health research, the adequacy of its funding and the extent to which best practice is disseminated.

o. the adequacy of data collection, outcome measures and quality control for monitoring and evaluating mental health services at all levels of government and opportunities to link funding with compliance with national standards

the potential for new modes of delivery of mental health care, including e-technology

Appendix 2

depressioNet User Survey 2004

The following table gives results taken from the depressioNet User Survey conducted in November 2004 and provides an insight into the areas in which depressioNet is able to empower people to make informed choices and find solutions.

There were a total of 722 respondents for this online survey.

Due to lack of resources the results are currently only available at a very basic level. All results given below have as their 'base' all respondents. Additional resources for analysis would provide more informative results. For example it would be useful to know the proportion of people who are in the workplace who consider that depressioNet helped them to be able to continue to work while having depression.

Using depressioNet helped me . . .	Agree + Strongly Agree
To understand that I am not alone	87%
To better understand the symptoms of depression	81%
To learn the way I can help myself	78%
To better understand treatments	71%
To better manage the symptoms	62%
To access treatment	29%
To find professionals in my area	31%
To find support groups in my area	30%
To learn how to better help a family member or friend	33%
To learn to gain the support I need from family members	33%
To improve the support I received from family and friends	35%
To be able to continue to work while having depression	41%
To improve my performance at work while having depression	39%
To be able to return/start work	28%
As a student/teacher/academic	20%

Note: While 28% of respondents overall stated that using depressioNet helped them to be **able to return to / start work, this rises to 40% for those with depression and/or anxiety only** (people with other mental illnesses were less able to return to work)

Some further results have been obtained from this survey and are available upon request.

Appendix 3

The Impact of the Current Mental Health Industry Model on depressioNet

When the depressioNet.com.au site and service was first established, it was aimed to meet the needs of people living with depression.

depressioNet aims to: increase understanding of depression -> reduce the stigma PLWD feel towards having depression -> encourage and assist access to treatment -> support and encourage during treatment -> educate regarding ongoing management and/or relapse prevention. The average time taken for this process is 4 months. Hence after 4 months, most PLWD no longer need the depressioNet communication forums daily. Most will visit only weekly or no longer visit at all soon after this time period, returning only to provide the assistance they received – to help others.

However, early in 2003 it became obvious within the messageboard that there were different 'groups' of users who had directly conflicting needs! An initial analysis and review revealed that there are two distinct segments of people using depressioNet.

The first is that segment for whom depressioNet was created – those whose aim is to recover/ live without the symptoms of depression impacting their lives and for whom this is possible within a relatively short period of time. This is the segment that represents the greatest proportion of people living with depression (PLWD).

The second segment consists of people who are seeking 24-hour peer support and 'community' on an ongoing basis. Further investigation showed that this second segment consists of people who have other mental illnesses which are more difficult to treat, will impact on their lives long-term and for whom depression is a side-effect of this other illness. The people in this segment are generally those represented by 'Mental Health Consumer' groups (MHCs) and are long term, high users of mental health services. MHCs have ongoing support needs that vary in nature but are more focussed on accepting and dealing with an ongoing chronic condition for which there is no treatment currently available that gives an expectation of elimination of symptoms.

As more MHCs came and stayed, the culture within depressioNet slowly changed so that it became more appealing to MHCs while slowly meeting the needs of PLWD less and less – hence fewer PLWD utilise it and the culture changes ever faster.

We have been aware of this issue now for 2 years. Not wanting to turn anyone away, we have done our best to accommodate as broad a base as we can, against the well-meaning advice of 'experts' from within government and the mental health industry.

Finally, we now have developed a model and strategy for implementing this model that will provide separate 'dNet Centres' to better meet the needs of specific segments. Importantly, it will not be diagnosis or labels based on health that will govern which centre any individual uses, rather the culture within each centre will allow the individual to self-select which centre best meets their individual needs.