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SENATE

SELECT COMMITTEE ON MENTAL HEALTH

Reference: Mental Health

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SENATE
SELECT COMMITTEE ON MENTAL HEALTH

Members: Senator Allison (*Chair*), Senator Humphries (*Deputy Chair*), Senators Forshaw, Moore, Scullion, Troeth and Webber

Senators in attendance: Senators Allison, Forshaw, Humphries, Moore Scullion and Webber

Terms of reference for the inquiry:

To inquire into and report 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 coordination 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 custody, 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 minimising 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; and
- (p) the potential for new modes of delivery of mental health care, including e-technology.

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Committee met at 9.05 am**KENNETT, Hon. Jeffrey, AC, Chairman, beyondblue: the national depression initiative****YOUNG, Ms Leonie, Chief Executive Officer, beyondblue: the national depression initiative**

CHAIR (Senator Allison)—This is the third hearing of the Senate Select Committee on Mental Health. The inquiry was referred to the committee by the Senate on 8 March for report on 6 October this year. Witnesses are reminded of the notes they have received relating to parliamentary privilege and the protection of official witnesses. Further copies are available from the secretariat. Witnesses are also reminded that the giving of false or misleading evidence to the committee may constitute a contempt of the Senate. The committee prefers all evidence to be given in public but, under the Senate's resolutions, witnesses have the right to request to be heard in private or in camera. It is important, however, that witnesses give the committee notice if they intend to ask to give evidence in camera. You have lodged with the committee a submission which we have numbered 363. Do you wish to make any amendments or additions to that submission at this stage?

Mr Kennett—No, not to the written submission you have.

CHAIR—I invite you to make a short opening statement, after which we will go to questions.

Mr Kennett—We very much welcome this Senate inquiry. We live in great hope and expectation of what may be achieved both in educating the public of your work and findings and giving this issue greater priority among our political leaders. It was 1999 when I recognised a need for a national approach to issues relating to, as we described it, depressive illnesses. We say 'depressive illnesses' because it is a softer form of words to attract people to seek help, but in general terms we are talking about mental illnesses across the board.

That approach of a national focus on depressive illnesses came from the last COAG meeting I attended with my premier colleagues and the Prime Minister. It is interesting that today, as we sit here in deliberation, Petria Thomas, who is one of Australia's leading sportswomen, is on air talking about her experiences with depression as a national athlete. I know that is anecdotal but in part it shows you how far the community has come in the last few years in terms of opening people's eyes to depressive and mental illnesses. I guess that is in part why this committee is conducting these deliberations. We are not pessimistic about the opportunities that lie ahead; in fact, we are quite optimistic.

We all recognise that mental illnesses have not received the priority they deserve over the last 50 years. That is not to say that there have not been some substantial inroads and improvements in that time. Not all of our requirements have been met, obviously, but certainly steps have been taken forward. We are, therefore, not interested in trying to address what we cannot change, which is things of the past, but hopefully our work at beyondblue and this inquiry's findings will advance a better community appreciation and allocation of resources going forward.

It is true that there is an awareness developing among the community as a whole about issues relating to mental illnesses and depressive illnesses per se. It is our view that this increasing

public interest will continue to grow and will become a fairly major force going forward in seeking change. Again, that is represented by the number of people that are talking about their depressive illnesses, the demand for better services et cetera. Certainly, there is an awakening in the 21st century to the impact of this illness socially and economically and to how we as a wealthy community should be trying to both address the illness and prevent it wherever we can. This awakening is occurring at a very rapid rate.

It is true that part of our work is designed to reduce the stigma and to encourage people to come forward and seek help. You would appreciate that it is like any other illness, except it is not an obvious one. It is like every other illness in that it must be treated to be cured or to be managed, depending on the severity of the illness. One of our great challenges, particularly with men and with people in rural Australia, is to have them talk about their illness and seek help and treatment in order to return to as healthy a condition as possible. We are championing the cause to have this illness recognised as any other illness. Whether it be AIDS, breast cancer or a broken arm, an illness is an illness and it is not a crime to be sick.

We have a fairly uncoordinated approach to issues relating to mental health throughout Australia. This is partly because it has not been a priority in the minds of governments of all political persuasions for years or a priority in the community compared to some of the more 'popular' illnesses, if I can put it that way, although there is change taking place as we meet today. Some states are more proactive than others but all are better at addressing this issue today than they were five years ago and certainly 10 years ago.

I would like to concentrate in our brief opening remarks on what we might do going forward. You are well aware that mental health gets less than half of the percentage funding of the health budget that the illness actually causes. It causes about 13 per cent of the health cost to the community as a whole but it receives about 6.7 per cent of the health dollar, so there is a real argument that we must move forward from the position we find ourselves in to at least equating the expenditure with the burden of illness. That would see an increase of a substantial amount of funding. Funding on its own is not sufficient if it is not well directed and well spent.

There are two areas where we have shortages: services and facilities. In the area of services, we have insufficient doctors and insufficient psychiatrists. Perhaps we have sufficient psychologists, but they are not being used. There has been a slight change in that whereby they are now able to be involved in six consultations at the recommendation of a GP, but there are other professionals that could be used in the field. I am talking about senior nurses and others—maybe even in some cases teachers with specific training. The real question is: how do we provide sufficient services to a community that is becoming increasingly aware of the issues relating to mental health and depressive illnesses, particularly in rural Australia? Obviously, more services are congregated in metropolitan areas than rural areas. We have a lot more to do in that regard.

I remind you that some years ago in Victoria we introduced mandatory reporting for the first time. That led to a significant change in the number of people who were being reported for abusing children. It stretched our resources to breaking point, but it was better to stretch the resources and have the reporting in order to try to stop it than ignore it altogether. As we destigmatise issues relating to mental illness, there is an increasing demand on the very limited

services we already have. I think that is going to continue, which is why we need to address the issue of services.

The second aspect is that of facilities. When we went about deinstitutionalisation—which I happen to believe was a very good step for the community as a whole; I am not one of those who are critical of it—we saw some states were better than others at providing services around those people who were deinstitutionalised. But that is historical and the issue remains that we do not have sufficient facilities to meet the needs of those who do need help for different periods of time and we need different sorts of facilities that are more modern than the sort we had in the past. So we have this dual need at the moment for a different way of handling the need to provide services and facilities.

In trying to look at a constructive suggestion for the committee to think about in going forward, it is our view that to set up another body per se is not the answer. We have enough bodies in community dealing with different issues. It is how best we use the current resources to deliver a more coordinated approach to addressing the issues of mental illness across the board. I would like to put two suggestions to you, if I may. Firstly, this process, as far as when beyondblue started, commenced in about 1997 or 1998 and went through COAG in 1999. Today, in 2005, most premiers are very much aware of issues surrounding mental illness. We have a wonderful bipartisan approach to the issues right across the country and I think the awareness of the issues is such that they are clearly understood by the Prime Minister and others.

So it seems to me that, rather than having a separate body, we need to be putting this into place through COAG so that the premiers and the prime minister of the day are responsible for driving the change. If they are not driving it, with due respect, even ministers are not as direct in delivering results. So it seems to me that through COAG this group of men and women can establish a small body to oversee the coordination of understanding and making recommendations to drive both service and facility provision. This is not an illness that stops at a border. That is why I advocated the national approach in 1999. It is a national illness and it deserves a national approach which brings all parties together, not in conflict. I see addressing mental illness as being one of the great social challenges of the 21st century. With the goodwill that exists, there is a real chance of doing something quite remarkable about it in a reasonable period of time.

The second suggestion I would like to put to you is an observation based on having served in the political system for a period of time. I often ask myself, 'If I had my time over again what would I do differently?' It is often asked of me too. While I do not regret anything I did—generalising since—my layman's education over the last eight years of involving myself in this sort of work makes me realise more than ever that we as governments continually respond to situations. In the area of health we respond to illness—to sickness—but spend very little money on advocating and promoting wellbeing and good health. That applies to mental health as it does to a whole lot of other illnesses. I would like to think that at some stage our governments would actually be committing money to a regular program to encourage people to remain fit and to remain well, to avoid a lot of the illnesses that they are otherwise going to encounter on life's journey.

By way of example if I may: every day in the media we hear, see or read about deaths on our roads around the country. We do not hear about the injuries, only the deaths. But every day about

eight or nine Australians take their life—suicide—as a result of depressive illnesses. The number of those who die by their own hand is almost more than double those who die in a motor vehicle accident, yet we hear nothing on our radio or see on our television screen or in the press nothing to try to prevent that. In other words, we get this media concentration on deaths and then we have governments responding to deaths, but in the area of mental illness we do not have the same concentration on promoting good health and wellbeing as an ongoing program. So I am talking about a substantial shift in approach. I know it is not going to deliver results today and tomorrow, but I think it is quite realistic to suggest that as human beings, with all the things that are available to us, over five, 10, 15 or 20 years we can be a much better and healthier society than if we continue to just treat depression, mental health and other illnesses as they occur without having a proactive program in terms of our wellbeing.

We come to you today standing on the submission that we have put before you, recognising that there is growing public awareness of and goodwill towards addressing the issues associated with mental illnesses right across the board. We also recognise that, historically, mental health has not received the priority it deserves and that the funding does not equate to the health burden that this sector imposes and therefore we need more money. But that money should only be applied if we have a coordinated approach where we have benchmarks and other measurement tools in place that will address both service provision and facility provision.

Firstly, I believe that should be done through COAG—that is, the premiers and the Prime Minister having the opportunity to take on board and drive change—but, secondly, we should also address the other side of the coin: why are we always called together in response to a situation; why are we not drawn together from time to time in a role that will prevent a lot of illnesses from occurring in our society? So, as I said, we hope that this hearing builds on some of the very good work that has been done in the past. We also recognise some of the shortfalls. But if we were not optimistic about the future then I guess none of us would be involved in (a) this hearing and (b) the areas of work that we are currently involved in.

CHAIR—Thank you very much, Mr Kennett. Ms Young, did you want to add anything to that?

Ms Young—Just to reiterate that the speed of reforms that are under way in Australia's health system for diabetes, heart disease, cancer and so on are progressing well. However, it is not progressing at the same rate for mental health or depression—certainly not with a coordinated, integrated approach. So, reiterating what Mr Kennett said in terms of the need for this to happen, it is an important time. We have a million people with depression and mental illness in Australia and fewer than half are receiving health care. If that number of people had heart disease or diabetes I think there would be a public outcry. There is no public outcry as such, but there are now three separate inquiries into mental health under way in Australia and it is growing to become a public outcry. We have an opportunity to do something about it and we look forward to participating in and supporting the Senate's inquiry into this area.

CHAIR—Thank you for that and thank you for those two worthy recommendations; we will see what we can do to get those into the report. Could I start by asking you how we go about making allied health professional services available to more people. Obviously, the Better Outcomes in Mental Health Care initiative has given people access to some psychological services, but would you support better coverage under Medicare? What sorts of changes would

you like to see to make nurses more accessible as a front-line defence, if you like? Yesterday we heard about a local government initiative where hairdressers were receiving training so that they could assist people, seeing as they are in direct contact with people getting their hair done. Do you have any ideas along those lines?

Mr Kennett—The last one you mentioned I think is fantastic, mainly because there are people who are willing to take it on board. That is half the battle in this industry: you want people who are interested enough to be involved to lend some assistance. Often, for people with mental illness, just having someone to talk to who has some understanding can help quite considerably. But it starts at the top. The better mental health outcomes initiative is going a long way towards re-educating a lot of doctors. About 5,000 have received that training to date. But we have a problem with a lot of our doctors in that so many of them are under such pressure. They are ill, they are suffering depression and they have the second highest suicide rate of all the professionals. It is a bit hard if you go along for treatment and the person treating you either is not properly trained in the area that we are talking about or is suffering and self-medicating et cetera.

I think the recent change to allow psychologists access to Medicare is good, but it is not good enough. We have a whole field of trained psychologists out there. I know it is a cost to government, but it is part of bridging the gap between the health burden and what we actually expend. There is, of course, political discussion between the college of psychiatrists and the college of psychologists, but I think we have to put that aside and open up the opportunity for psychologists to be used in the front line rather than in the third or fourth line.

I think it is terribly important that if there are people who are willing to be involved—whether they be nurses or hairdressers, some of them will have received some basic training, and others might need training or retraining—their use be encouraged. I think it is absolutely essential. I spent a lot of time out in the bush, particularly in the drought-stricken areas of New South Wales and Victoria. Rotary has a van going around Australia. I will be going to a lot of outback towns with them and holding public meetings. It is terribly sad when you hear of and see families who are disintegrating and cannot get help. I get calls all the time from people around Australia. There are people who have had a son, husband or wife in desperate need of help. We have had to send them on a six-hour trip to Sydney to get help. We have lost a few along the way.

The utilisation of interested people in addressing this issue is terribly important. I think your hairdresser illustration is good because it is outside the square. We are not going to have enough psychiatrists in this country in the next 100 years. They certainly do not live in the right areas, and they do not look as though they want to move. So I am not holding my breath. But we do have psychologists more evenly spread, and we do have GPs, although the further away they are from the metropolitan centres the more pressure they are under. We have to be able to reach out to those who are willing to participate. Whether that is through an accreditation system after some training—which would be based on the level of training they have already received—matters not. Often the best support for an individual in need is the person who gives them time. The training is important, but often it is time that matters. So beyondblue would very much support the extension as quickly as possible of a range of potential parties interested in addressing the issue.

Senator HUMPHRIES—I would firstly like to go to a couple of statistical matters. You mentioned in your submission that depression and related disorders are more common among younger adults, with 27 per cent of people between the ages of 18 and 24 having one or more of the disorders. A graph on page 5 shows that substance use disorder is one of the disorders you are talking about. Do you see substance use disorder—I assume that relates to alcohol and illicit drug use—as a substantial part of the reason why that 18- to 24-year-old group is so overrepresented in these figures?

Mr Kennett—It is such an imprecise science; the answer is yes and no. One of the most worrying trends at the moment is the number of young people who are suffering anxiety and stress at a very early age. I am talking about primary school students. We have done a lot of research into secondary school students, but we are now going to extend that to primary school, where I do not think drugs and alcohol are as commonly taken as in secondary school. We are trying to understand better why so many of our young are stressed. There is a lot of evidence of the effects of drugs and alcohol post puberty. We often do not know whether depression comes first or whether it is my ‘axis of evil’, if I can put that way. Others have their own axis of evil, but mine is to do with whether it is depression that leads to alcohol and drugs. It is often hard to tell. But the rates are alarming, which is why we argue strongly for more preventive work.

A lot of information suggests that if we spent more time on dealing with young people at an early age, particularly around puberty, in terms of their anxiety, stress and depressive illnesses, we would help them return to good health quickly. If we do not get them then, the likelihood is that their situations are going to get worse as they go through life. So, in answer to your question, from my point of view, in part, yes, beyond primary school, but not while in primary school. There are different factors: marriage break-ups, lack of food and clothing.

Ms Young—There is also a reluctance to seek help or to even recognise signs and symptoms, and that is across the community. Young people are not interested in going to a GP or a mental health service, and they are less interested to tell their parents as well, but they do tell their friends. Through their peers they talk about how they are feeling and how they are not travelling well. They do self-medicate. They certainly take risks, but they also smoke and drink in an attempt to feel better. Across the board, we need to not only improve information and knowledge about the issues and the stigma and discrimination that are associated with mental illness but also make it less of a ‘shame job’ if they are not feeling well, and encourage young people to share that and then respond to it.

We talked about allied health having an increased role. Certainly people with diabetes, for example, even at a young age can be assessed, can be on a treatment pathway and can be working with the community nurse or a nurse at the doctor’s surgery or at the community health centre. They do not have to be within a treatment regime that says: ‘Oh, gosh, I’ve got diabetes.’ They can manage it at home. Much of that has come about because the information is shared, the pathways have improved and treatments have improved. If we can let people know that it is okay to have depression or to not be travelling well, if we can let them know to have it checked out and that effective treatments are available, we have gone a long way to taking away the shame of having such an illness. Also, it becomes better known in the community, and it is not such a shame to seek help.

Mr Kennett—One of the things we hear from teachers—and I am sure you do—is that they spend more and more of their time worrying about the social issues surrounding their pupils than they do worrying about their educational needs. It is the way the child presents. It is a very worrying trend, which is why I think this early intervention is so important at a young age.

Senator HUMPHRIES—You talked about prevention. When we talk about prevention, are we not talking almost exclusively about early diagnosis and early intervention? Are there any strategies that help prevent mental illness in the way, for example, we can prevent heart disease by exercising, not smoking and things like that? Are there really any strategies of that kind that we can use?

Mr Kennett—I think there are, with due respect. It is about this issue of wellness. I really think it is terribly important. A lot of people when they suffer a depressive illness can be cured once they seek treatment and they have the correct diagnosis. As we know, with a lot of people it is hard often to get the correct diagnosis, particularly quickly, because the doctor has to almost experiment. It is not always about drugs. It may be drugs initially, but it is about quality of life and self-esteem. From some of the work we are doing with children in particular, it is as much about self-esteem. They feel so terribly under pressure or isolated et cetera.

There is this concept of early intervention, of prevention, of lifestyle. I go back, unfortunately, to the introduction of television and all its manifestations since then. I cannot help but believe that television has done this community a huge disservice because it has stopped families sitting around the table eating. It has stopped people exercising. And, since television, we now have computers and computer games. Lifestyle has changed quite dramatically. The speed of information has changed equally quickly. There are different tensions.

We have to get that balance. Maybe it is just an ageing thing that happens as we get older, but you have to get a balance into a person's life that is about wellbeing. That is why I argue that, if we could have one per cent of the budget spent on the prevention of illness, on wellbeing and on helping young children get a quality of life and get the right values it would be the cheapest investment we ever made. In certain cases, yes, it is more difficult but, as a generalisation, it is certainly something that is well worth pursuing. Again, as I say, if I had my time over again, those would be the sorts of things I would do.

Senator HUMPHRIES—I will take the *Hansard* home and show it to my children. I have had that very same conversation about television in the last few days.

Senator FORSHAW—Thank you for your submission and for the good work you are doing. Many years ago, through people I knew who were suffering depression and who had breakdowns—this is going back many years—I became aware of a group called Recovery, which I think is now known as GROW. The question I want to ask you is: what interaction does beyondblue have with the various groups? I think some people call them consumers or patients. There are quite a number of them around the country. They are very poorly funded or they receive almost no support. It seems that they have, for many people, a positive role which is similar to those of other self-help groups—and that is probably a very poor term to use. I am interested in beyondblue's work in relation to consumer groups. Also, you have said that we need to have an extra \$1 billion spent. I gather from your remarks that one of the priority areas is in promoting wellness and wellbeing and that preventive aspect. What priority areas would you

see if you had that \$1 billion tomorrow or over the next four years? It seems to me that one area is giving more support to groups like GROW and others.

Mr Kennett—Let me start and Leonie can finish and clean up behind me, no doubt. If I said \$1 billion, I did not mean \$1 billion. The actual differential between—

Senator FORSHAW—It is in the submission. Whatever it is, I do not disagree; we need more money spent.

Mr Kennett—Yes, but I am not here to argue for more money without trying to provide a solution. The actual differential is about \$4 billion over the burden of the illness and what is currently being spent. Thirteen per cent is the burden. It is 6.7 per cent of the health budget; to get it up to 13 per cent is about \$4.5 billion. On top of that, I would also argue—if I had any influence at all; I recognise that I have none—for one per cent of the federal budget to be spent on a separate wellbeing campaign, so that is about \$2½ billion. It is just such a wonderful investment to do it.

Your point about there being many groups is absolutely right. There are a lot of groups, and there is an increasing number of groups because this is an area that is coming into its time. There is no doubt about that. Some of our mental health institutes which were dealing specifically with mental illness such as schizophrenia are now extending their activities into depression because they understand that this is an issue that is coming into its time. But our priority has to be destigmatisation. We have to get people to feel comfortable to come and seek help, and that has been a lot of the work that we are doing. If they do not seek help, they cannot be cured, they cannot return to good health or have a manageable career.

But we are recognising that we have to have better services, more people involved and better facilities. We have our priorities. We commission research, as you know, we are developing a lot of educational programs, we are working very hard with the medical profession and professionals to upgrade their skills and to have them better available to communities, and we are certainly working with people such as those in the insurance industry to change a lot of the rules that discriminate against people with mental illness. I am afraid there is still a great deal of discrimination. That is why I argued for a public inquiry into the Cornelia Rau situation—not because of what happened to her personally in any one of those facilities that she was held in, but to find out how a person with an illness could be transferred from one jurisdiction to another without anyone saying, ‘This lady is ill.’ It is a real worry.

We deal with a lot of consumer groups. There are many of them. We are not ourselves a funding group but we do certainly work with some where we can. I will ask Leonie to mention the spread of the consumer groups that we deal with, but the priority must be public awareness, as it was with AIDS. When AIDS came to this country many years ago, many of us were horrified by the acts that caused most incidents of AIDS, but through better education and understanding and better sex practices we achieved less illness and certainly fewer deaths.

A better example in this day and age is breast cancer among women. In the last 15 years that has been the most wonderful campaign. Women now regularly check themselves out and get checked. It is talked about freely and people are not ashamed to talk about the illness. We have not arrived at that stage yet with mental illness, and that should be the test. When we get to that

point, I can retire, because we will have achieved an ability, particularly for men—they are different from women. Women have better relationships with doctors and they talk more among their friends. Men are not as good, and country men are hopeless, because they are born to be tougher than John Wayne. They are using all sorts of methods to avoid their responsibilities. So we are trying to reach out to those people, but we do it in many ways.

Ms Young—One of the ways we do it is by supporting consumers, or people with depression, and their carers. You asked a very important question about self-help groups, and there are many across Australia for people with mental illnesses. They all support their cause or their purpose and indeed the people around them. What beyondblue has done, though, is to put the focus on each person's experience with depression and to make that experience known to policy makers, service providers and so on. So we do not work in a self-help or support group way at beyondblue but we do support people with the illness—and their carers—to raise their voices.

We have an organisation called blueVoices, which is our consumer and carer arm, and, as Jeff said, there are various groups under that. They cover the key and important areas that are not well recognised and have a disintegration of service response. They include bipolar, postnatal depression, depression in the elderly, anxiety and various other depressive or depression related disorders. We support the raising of that voice in sharing information about the illness and its effect on people. We do support GROW and any other mental illness support group with our information. Our focus, though, has been on raising awareness of depression across Australia and tackling the stigma and discrimination associated with it.

Senator FORSHAW—My question was not intended as a criticism of anyone.

Mr Kennett—No.

Ms Young—No.

Senator FORSHAW—It was more about how we actually give those groups more support—

Ms Young—A greater voice and more support.

Senator FORSHAW—but also get more coordination and integration.

Mr Kennett—It is partly why I think we need to have this. We are getting to the stage where there are so many people with goodwill getting involved in this area of health that we need a better coordinated approach. When we started advocating the need for a national approach it was to make sure people came and sought treatment. Michael Wooldridge and, I have to say, the Victorian government here were both very good in allowing us to establish beyondblue. But they did it because, at that stage, the mental health and depressive illness industry was fragmented. It did not have a lightning rod, and I and beyondblue have become a bit of a lightning rod for the industry to lift awareness et cetera. I think collectively we have done that reasonably well. The issue is how we move it forward now, because our advocacy was for a national approach and for destigmatisation—getting people to seek help. But, because of past practices and increasing demand as people come out, talk about their illness and seek help from different organisations, how do we now best manage the next 10 or 15 years for this industry sector?

That is why I make the suggestion that, rather than set up a new body entirely, which is probably going to be resisted by a number of politicians for a number of reasons, it is better to use the framework that we already have, which is COAG. We should understand the value of having the premiers, chief ministers and Prime Minister being more aware of this illness than ever before and charging them with the responsibility of overseeing the next 10 to 15 years in this terribly important area, not only socially but also economically, because of the cost of depression. There are an increasing number of support groups, which are doing very good work—and people respond differently to different groups, different people and different emphases, and there is no one solution, which is why every group is potentially important. If we are able to do what I am suggesting then it will lead to a better coordinated approach where we can measure outcomes and certainly set better standards. The real worry is that with a lot of these groups people are getting bad advice, even though the people associated with them are trying to do good work and most of them are doing good work. But there is nothing worse than giving a person in need bad advice.

Senator WEBBER—I will get in before Nigel Scullion and congratulate you on actually focusing on efforts in rural and regional Australia. I am from Western Australia so I have a particular interest in that. I would actually say before I embark on my question that Curtin University is about to start trialling some prevention campaigns in regional Western Australia, mainly in the north-west. They are calling it the ABC or Act Belong Commit campaign. It will be interesting to see how that goes. I was particularly taken with the section of your submission on Indigenous communities. In the Kimberley we have people as young as eight committing suicide. It is obviously a problem. I was wondering if you could expand on what you have said. What do you think we can do to actually start attracting these people into the health system in the first place so that we can then start recognising and treating their mental illnesses?

Mr Kennett—Leonie will explain the programs. It is not only young people, obviously, in the Indigenous communities. There is often a series of suicides. What do you call those, Leonie?

Ms Young—Copycat suicides.

Mr Kennett—That is right. It is just appalling.

Senator WEBBER—That is what is happening in the communities.

Mr Kennett—It is shocking. It is in South Australia, Western Australia and certainly up north. We are getting a number of programs into place, but, again, the community has not had the treatment it deserves for a number of years. One of the other aspects of this is that the Aboriginal community does respond very well to peer influences and particularly to footballers. Most Aboriginal communities are involved in football. We are actually looking at the moment at incorporating one or two of these people, properly trained—and there are a number who have suffered depression but who are very good communicators—to try to lift self-respect amongst some of the communities. The important thing is not to go in and conduct a program and then leave them. We have to have a method of going back every three months, six months and 12 months. That is fairly costly, but it has to be done. You cannot just go in once and think that you have educated someone.

Leonie, who has served in the Northern Territory, is well aware of the issues. We are looking at a number of programs which are currently running. Mike Rann in South Australia is asking us the same thing in terms of his community. But to argue just for programs is not sufficient. We have to have continuity and we have to introduce an element of peer support, which they respect. In terms of these copycat suicides, in Swan Hill in Victoria in the last year we have had 12 or 14 suicides. Three of them have been from one cricket team. These are young men. You cannot tell me that there is not something seriously wrong or astray when you get that in a small community. Unfortunately, although the Aboriginal communities are smaller, the number of deaths is higher. It is frightening.

Ms Young—There is a great deal of work to be done in the area and a suicide prevention strategy or a health strategy or a depression initiative cannot tackle it on their own. The health, education, welfare, employment and social issues are profound. So it needs a whole-of-government, whole-of-community approach and, importantly, it needs to be led by people in the community in terms of going forward. That is a broad answer to a very specific and profound issue for us.

However, higher rates of unemployment, less adequate housing, shorter life expectancy, lower levels of education and higher rates of imprisonment are significant issues for people living in remote communities. The attention that is given to crises and the enormous and profound issues for families living in overcrowded housing, for example, are all contributors to acts of impetuosity or risk-taking behaviour—a whole range of things—and we are, from the sidelines, looking and saying, ‘This is a huge issue; how do we deal with it?’ How beyondblue went about it was to work with communities—particularly to work within the health structure in communities and the local government structure within communities. It is a simple program in terms of a community development approach, but it has been working really well in terms of having an Indigenous liaison officer or mental health officer within each community, who works with the GP, the primary care health clinic or whomever. Those people, though, are front-line people, 24 hours a day, seven days a week and it is not enough to give the responsibility for the community’s mental health to one person or a number of people, just as it is not enough to have a health centre and think, ‘That’s enough. Why can’t that community go to the health centre when they need help for an illness?’

It really takes a broader, new, bold approach to looking at these things in association rather than in isolation, and beyondblue, in looking at this, is part of a social coalition—with the Australian Indigenous Doctors Association and, importantly, with a number of Aboriginal organisations—with a focus on health. Focus on holistic health is really important rather than focusing on one or two areas. Looking at young children, though—as young as eight—committing suicide is, I think, an urgent issue for us as a country. It is not just a community’s responsibility, and it is something that we at beyondblue are interested to do some more—urgent—work on.

Senator SCULLION—I very much enjoyed your submission, Mr Kennett. I have almost forgiven you for stealing Leonie Young from the Northern Territory.

Mr Kennett—Change is often a good thing, as you would appreciate.

Senator SCULLION—I understand that—in some circumstances. It was interesting to note, when you were talking about focusing on coordination, your very sensible comments regarding COAG and how we not only need leadership but also have to have a unified approach. It is a very difficult issue. I am looking at the program. We have beyondblue—and I will leave a few of the others out—we have the Victorian Mental Awareness Council, we have the Mental Illness Fellowship of Victoria and we can go through the submissions. It strikes me pretty hard between the eyes that each submission says exactly the same thing—they are doing their best and they are all saying: ‘We want more money. We are all out there. We want more money for psychiatry services in rural Australia and for awareness. We’re aware of the stigmatisation issue.’

You talk about a coordinated effort. The government, no doubt at all levels, provides taxpayers’ funding of some form or another to all these different bodies. Talking about the Indigenous area just for a moment, we have, I think, 2.1 people—more than twice the amount of people in terms of demographics—who take their own lives. I have only been at two days of hearings and I have heard four separate submissions dealing with different issues dealing with that area. You are dealing very sensibly with it by having workers deal with GPs. Two separate programs are being delivered in the same college—Batchelor—by separate people. There is a plethora of stuff and, with the best will in the world, it is not being coordinated at all and there is a lack of capacity, I think, for us at any level of government to dictate to somebody how they should do their business. It is obvious that, when we have a more coordinated approach such as, ‘We’ve decided that the funding for this goes to somebody,’ and, ‘This is your specific role,’ it will be far more effective. What do you think about the role of government in doing this task more effectively?

Mr Kennett—You will have already observed, but you will note it the longer your political career goes on, that politicians often try to satisfy everybody, particularly those who make the loudest noise. The difficulty is that that is not always the most efficient way to work in terms of delivering outcomes. I am not interested in more money if it is not correctly managed and if it is not up against some very strict measuring rods. I would also say that the only way you are going to get the sort of simplistic approach that I think you are referring to, which I would agree to in terms of management, is if you have got someone who is driving the issue—and mental health is not an issue that has perhaps ever been driven by anyone in politics in a position of influence that I am aware of. It is not as though any Prime Minister of the day has had such an interest in mental health that they wanted to drive it. I think it is the same with any premier. I have not found a premier who passionately believes in the issue to the point of taking such an interest that they want to drive it. I think that is the only way you are going to overcome this duplication.

Again, in one sense I consider this work I am doing now to be more important than anything I have ever done before. If I had my time again, I would do perhaps everything I did before but I would have a new focus on mental health. If the head of government is driving it to the point that he says, ‘All right, there are 50 groups out there; we don’t mind you all doing your work but we’re going to insist in terms of funding that we coordinate your work so that there’s no overlap and everyone has their own specific sphere of activity,’ it is only then that you are going to get the simplistic solution that I think you are referring to. And it is difficult.

That is why I ask this Senate committee, when you have listened to everyone and you make your findings and recommendations, to be bold—for goodness sake. The last thing we want is another insipid report, with due respect, that gets completed and put on a shelf. I think this is a

moment of wonderful opportunity. I am not depressed at all about the situation of the industry. I recognise there is a lot more that we can do, but I am very excited because I think the community are waking up; I think they might become a political force. If you put together the people associated with depressive illnesses—the affected, their carers and the aged, an area where depression is rife, obviously—you have got five million people. If they ever got their act together, politicians would be listening to them very quickly. The question is whether we act in advance of that in the interests of good governance, and I think, Senator, that is what you are talking about.

When beyondblue was established, cleverly it was established by someone as a private organisation. We are not a quango; we are a separate company. We get most of our funding from government but we cannot be dictated to by government. We respect our stakeholders, who are governments, but we are separate and therefore we are able to do our work according to our priorities.

Rather than set up something entirely new for mental health, which is a temptation, and say, 'Let's have a new mental health body,' I would probably argue, 'To save time, it's better to do something through COAG,' because there is a lot of goodwill about premiers and somehow or other you have got to challenge them, and the Prime Minister, to make this work now. As this issue becomes bigger and bigger in the community, we need to get it into a coordinated form where the things that you are talking about are right. You are not going to please all of the people all of the time; politicians cannot do that, although we try. But what you can do is have a greater influence on the outcomes, and that should be our first priority. If we improve the outcomes then we will get the community's support in return.

That is why I think that this moment is such a wonderful bipartisan opportunity: it is so well supported by all sides of politics that it is just remarkable. It is the most bipartisan thing I have ever been involved in, and I think that is why I am so hopeful about it and why I am so opposed to this continual reporting of efforts in the community that have supposedly failed for so many years. Yes, we have made mistakes but we also have the opportunity to do a great deal of work. Be bold.

CHAIR—I think that is a very good note to end on. Thank you very much, Mr Kennett and Ms Young. It is a great submission and it was good to have you before the committee.

Mr Kennett—Thank you very much for your time. We would like to leave some material with you, if we may, for your deliberations.

CHAIR—Is it the wish of the committee that this work be tabled?

Senator FORSHAW—Yes.

Senator WEBBER—Yes.

CHAIR—It is so ordered. Thank you.

Mr Kennett—Thank you very much. Have a good day.

[10.00 am]

COGLIN, Dr Michael, Chief Medical Officer, Healthscope Ltd

WILLIAMS, Ms Susan Malena, National Manager, Psychiatry, Healthscope Ltd

CHAIR—Welcome. You have lodged with the committee a submission, No. 82. Do you wish to make any amendments or additions to that submission at this stage?

Ms Williams—No.

CHAIR—I invite you to make a brief opening statement, after which we will go to questions.

Ms Williams—I thought it might be worthwhile if, by way of introduction, I outlined who Healthscope are and what we actually do. We are a publicly listed company. We have 34 hospitals nationally. We are the third-largest private provider of hospital services in Australia. We provide services in acute, med/surg, rehabilitation and psychiatric services, and I coordinate the psychiatric hospitals for the group. We are the largest private provider of psychiatric services in Australia. We have 11 hospitals or units providing psychiatric services across the eastern seaboard and Tasmania, and we treated over 5,000 in-patients and in excess of 12,000 day patients last financial year.

We have addressed two of the terms of reference in our submission. The one I would like to speak to today is term of reference (d), ‘the role and function of the private sector in the provision of mental health services in Australia’. The points we have tried to emphasise in our report are that really we have two very distinct systems operating in Australia. We have the public sector which, primarily as a result of its legal responsibility to take involuntary patients, largely cares for patients with schizophrenia, severe psychotic disorders and severe depression. We have the private sector, which caters for patients with more high prevalence disorders such as depression, anxiety and drug and alcohol disorders. As you will have heard from numerous statements, depression is predicted to be the major burden of disease by the year 2020. To reinforce the contribution of the private sector to mental health in Australia, private hospitals contributed 40 per cent of in-patient bed days in Australia last year and something like about 65 per cent of same-day services. So we are certainly contributing to the mental health system.

The point we are concerned about is that the shortage of beds in the public sector is now the norm. Every day there is something in the paper about patients being cared for in the emergency department by agency nurses. This is not an appropriate environment for patients to be cared for in, and it is costing the government a significant amount of money. In contrast, the private sector has grown quite significantly and has the flexibility to increase its capacity. We propose a solution whereby the private sector could assist with the problems of bed block in the public sector by providing some private in-patient beds on either a short-term or a long-term basis.

This could be done in a number of ways. We could look at decanting patients directly from the emergency department into private hospitals on a short-term basis. There could be improved triage of private patients presenting to emergency departments—those patients could be

redirected to private hospitals. If the patients were too unwell to be decanted from the emergency department you could look at decanting patients who are more stable from the ward area to a private hospital for the last two or three days before their discharge. Their care could be coordinated by case managers from the public sector, to ensure continuity. Or you might look at buying some beds from the private sector while money is being invested in capital works to increase the bed stock in the public sector.

The economics of it are pretty compelling. By way of example in our paper, it costs approximately \$1,500 for an agency nurse to care for a patient in the emergency department for 24 hours, whereas you could probably buy a bed in the private sector for \$500 a day. So we think that is pretty compelling.

The other point we would like to make is in relation to term of reference (d) and the duplication of services. The private sector has a number of specialty programs in relation to psycho-geriatric care, eating disorders, substance abuse disorders and youth. If there is duplication across the two systems perhaps there could be purchasing of services between the two systems. I will hand over to Michael Coglin, who will talk about the health fund issues.

Dr Coglin—Thank you for the opportunity to make representations to the committee today. The issue that I would like to draw your attention to is the behaviour of the 41 registered health benefits organisations—health insurers—in relation to the funding of private psychiatric care, particularly in-patient private psychiatric care, for the sickest of their members in the nation's private psychiatric hospitals. In particular, I want to draw attention to the issue of portability of health fund membership between different funds for a given consumer.

I will start with the portability issue. In 1988 the Commonwealth passed legislation which, for the first time, recognised the significance of portability as an essential consumer protection for citizens belonging to a private health fund. To summarise the letter and intent of the original legislation in 1988, the provision attempted to state that if you belonged to health fund A and you had served all relevant waiting periods with that fund you were entitled, as a matter of law, to transfer to a comparable table in health fund B without the imposition of new waiting periods that would apply to a person joining that fund with no prior affiliation with a health fund. Over the years, the right of consumers to move from fund to fund without penalty has become increasingly significant for a variety of reasons, which I will explain. The issue has never been more significant than it is today, and nowhere is it more significant than in the case of a patient suffering from chronic mental health disorders.

In 2003, I believe it was, there was a dispute between a major national private hospital group, Healthscope, and a major national private health insurer, the BUPA health fund, which traded in South Australia as Mutual Community, in the Northern Territory as Territory Mutual, and here in Victoria and the eastern states as HBA. The dispute was a commercial dispute and one of the outcomes of that dispute was that BUPA were disinclined to contract with certain Healthscope hospitals—particularly hospitals involved in mental health services and specialised physical rehabilitation hospitals—which guaranteed access to its members.

Under the provisions of portability, members of BUPA who were disaffected by their health fund's purchasing choice had the option of joining any of the other 40 health funds that did have a contract with their preferred hospital. In response to a wholesale transfer of members—

variously estimated at between 5,000 and 10,000 people across all the states affected by this dispute—one health fund in particular, Australian Unity, sought to impose what they called a ‘fund rule’, with the approval of the Commonwealth department. In effect that said that a transferring BUPA member joining Australian Unity was required to wait, I think, 12 months—it may have been two years, my memory fails me on that point—before that joining member at Australian Unity could access private psychiatric benefits at the Australian Unity contracted hospitals.

Let me walk you through the scenario faced by a BUPA member who may have a lifetime association with a psychiatrist—obviously not all psychiatrists work in all hospitals—who is affiliated with, say, the Melbourne Clinic, Australia’s pre-eminent private psychiatric hospital, which is operated by my company. If the patient is a BUPA member, in this post-scenario dispute they have three choices. They can come into the hospital and have approximately half the hospital fee paid for them by their health fund. The health fund cannot decline to pay any benefits for psychiatric care, but in an out-of-contract scenario the obligation is limited to about 50 per cent of what the hospital would normally charge. That is prohibitive. The average length of stay at the Melbourne Clinic is around 18 days. The out-of-pocket costs for that person are about \$250 a day. People with chronic mental illness typically are occasional participants in the work force and do not have high levels of income and savings, so the imposition of a \$250 a day out-of-pocket cost for a protracted hospital stay, with the possibility of recurring admissions going forward, is not an option.

Alternatively, the patient could change to a BUPA contracted—that is, BUPA preferred—hospital, but typically that would involve a change of psychiatrist. As I am sure you would intuitively recognise, the relationship between a patient with a chronic psychiatric disorder and their psychiatrist is far more important than the relationship between that patient and an insurance company—or a hospital, for that matter. Finally, the patient could transfer to another health fund that had a contract with the Melbourne Clinic and the problem would go away. The behaviour of Australian Unity, which is keenly watched by other funds in the industry, erodes that third option to the point of destruction.

There are a number of other techniques which I believe are employed by some health funds to discourage people with psychiatric illnesses from joining and remaining as members or, if all else fails, from accessing reasonable benefits. I am happy to provide details of some of these techniques, if called upon to do so. The first of them involves the provision of exclusion products under which people are invited to take out membership of a particular table and then unexpectedly suffer from a disorder. It could be heart disease, a pregnancy requiring obstetrics admission or, in the case we are talking about here, a mental health disorder. The product they have chosen on the trade-off of price says, ‘We don’t cover you for certain diseases.’ Our view is that products containing a mental health exclusion are not fit for purpose and should not be allowed to be offered by health insurers, because of the unpredictability and prevalence of mental illness in the community.

The second behaviour which enshrines the need for portability is the increasing practice of health funds selectively contracting with hospitals for commercial reasons. Australia’s largest health insurer, Medibank Private, is currently engaged in a large-scale exercise the purpose of which is to discriminately choose—as they would have it—hospitals where the members can be treated, and therefore they do not have contracts with hospitals where their members would be

disadvantaged. A patient choosing or preferring that hospital needs access to portability if they do not agree with their health insurer's purchasing choices. That person is entitled to say, 'I don't like the fact that Medibank Private doesn't contract with the hospital I have been going to for 20 years, and therefore I would like to transfer to some other fund that does.' Portability is the essential route to allow that patient to continue accessing their hospital and doctor of choice.

Thirdly, some health funds have placed a freeze on new psychiatric units or programs and, in particular, they are disinclined to fund expanded mental health services in remote and rural Australia. Their inability or refusal to support the modest attempts of companies like ours to introduce mental health services to the private sector in remote and rural Australia—our most recent experience was in Burnie, Tasmania—basically strangles at birth any attempt to introduce those programs.

CHAIR—Can I interrupt you there. We have your submission. The committee is keen to ask you questions. I encourage you—

Dr Coglin—I am happy to stop there.

CHAIR—Excellent.

Senator HUMPHRIES—Dr Coglin, I want first of all to come to the issue you have raised about insurance. You mention that Australian Unity adopted a policy of not allowing people to take up the rate of payment for services for mental illness when people transfer to them from another fund. Do you mean that they were prohibited from taking up Australian Unity's offer of coverage at the rate that Australian Unity offered it or that they were not eligible for any coverage at all for that 12-month period?

Dr Coglin—What they said was that if you transfer to our fund from another fund to a comparable table you will wait X months before we will pay full benefits for you to attend a hospital where we have a contract. If you happen to have diabetes or renal failure or some chronic relapsing incurable physical disorder, we will not impose that on you: you can come on board as a laterally transferring member from BUPA or any other fund and we will treat you from day one as a fully paid up member with no waiting periods. Only in the case of people with mental health disorders or people requiring rehabilitation will we impose on you a period of a year before we will pay your hospital the amount we would pay for our normal members. That is discriminatory, in our view.

Senator HUMPHRIES—It was suggested to us yesterday by the funds organisation, the Private Health Insurance Association, that their policy was that people could transfer over but they would receive benefits at the rate of their old fund for a 12-month period and not move up to the rate paid by the new fund until that period of moving in had expired. You are saying that is not the case and they will get no benefits at all for 12 months.

Dr Coglin—They would get what is called the ministerial default benefit, which is the minimum statutory benefit, which typically is about half the contracted price that would exist where a contract exists between Australian Unity or any other fund and the hospital. In a mental health hospital, the fund would have as its contracted price—in round figures—\$500 a day. The

minimum default benefit would be \$250 a day. The patient would have to find the other \$250 a day above that.

Senator HUMPHRIES—There was a spirited defence by Mr Schneider yesterday of the right of funds to not automatically take transferees. He suggested that what was happening was that some doctors in private hospitals were effectively brokering particular deals for their patients. If they felt another fund would give their patient a better deal, they would simply move them over to that. He said that it is not possible for a person to walk up off the street and join a fund with a pre-existing condition so why should it be possible for someone in a fund which is not giving them such good coverage to simply move over and not have a waiting period? There is a point to that, isn't there? Why should a person be able to get the benefits merely because the doctor considers they will get a better deal in that particular fund?

Dr Coglin—My colleague may have an answer but there are two things I would say there. Firstly, the relinquishing fund—that is, BUPA in our case—has enjoyed the membership and premiums of that individual, in some cases for a lifetime. They are quite happy to take the money from the patient. But when it comes to paying the benefit, they are less enthusiastic about meeting their responsibilities. I do not know whether I am—

Senator HUMPHRIES—If BUPA has a person in their fund for a long period of time and the doctor says, 'You'll get a better deal with Australian Unity, so we'll move you over there,' under the arrangements you are suggesting they will be able to that without any penalty or any problem.

Dr Coglin—Sure.

Senator HUMPHRIES—BUPA then does not have that patient any longer; they are covered by Australian Unity. They pay a higher benefit, but they have not had the advantage of 20 years of membership of that patient.

Dr Coglin—Exactly right. Our view would be that the correct adjustment there would be for BUPA, who have enjoyed years of contributions from that member, to somehow compensate the new fund, Australian Unity, for the benefits that Australian Unity have to pay for the transferring member. That has nothing to do with the price the hospital is paid. That is neither here nor there. BUPA, by declining to purchase certain high-cost services for chronically ill people—in this case, only mental health services at these hospitals—is in effect driving high-drawing members into other funds, who rightly and understandably cry foul. The answer to the inequity in that is for BUPA to reimburse the gaining fund for its exposure, based on the fact that BUPA has enjoyed that member's contributions, often for years.

Senator HUMPHRIES—I am not sure that it is fair to argue that a fund that is losing a member should contribute to the benefits that are being paid by a different fund. They would say: 'We offer a benefit; people know what our benefit is. If you choose to move somewhere else that is your choice, but we should not have to contribute to the benefits.'

Ms Williams—The doctors are not as sinister as the health funds make out. They are not really interested in the commercial aspects of the hospital and the health funds; they are interested in continuity of care for their patients.

Senator HUMPHRIES—Yes—but you can understand the funds' position: why would they pay for somebody who is moving away from their fund?

Ms Williams—But there are reasons why the doctors are encouraging patients to move. They may have had a 10- or 15-year relationship with a patient, they no longer have a contract with the hospital, and they have said, 'Move to this health fund and I can continue to treat you.' That is the reason why they are encouraging their patients to move.

Senator MOORE—Yesterday, as Senator Humphries has explained, we had a discussion with the health funds organisation and we particularly asked them whether or not they could show where there were any other areas, apart from mental health, which have had this preclusion put on them. We are waiting with interest to get their response. The whole area of portability came up a lot, so you can be confident that that will be considered.

I am interested in the information you have put in your submission about the relative costings of public care and private care. Have you had these discussions with various government agencies, pointing out this rationale? If you have, what has been the response?

Ms Williams—We have had a number of discussions with government.

Senator MOORE—I am sure you have.

Ms Williams—We have been in discussion with the Victorian government for 18 months. As you would be aware, there has been a lot of publicity in Victoria in recent months. We are coming closer to brokering an agreement but it has been torturously slow. It is compelling: you have agency nurses that are not committed to the hospital; half the time they are not psych-trained nurses but they are caring for patients in the emergency department who are psychotic. It is really inappropriate. And the agreement is actually going to save the system money.

Dr Coglin—In the Northern Territory, being an example of a remote or rural Australian location, it does not make sense to have parallel, sophisticated and complex services in both the public and private sector that try to access limited skills in those communities. For example, in Darwin there is a single coronary angiography unit—cardiac catheter studies. It is madness to have one in the public system and one in the private system, so private doctors, the private hospital and the Northern Territory government collaborate in having a single service where the limited skills available in the Top End can coalesce, the capital investment makes sense, the throughput makes all of that viable, and the public patients get a terrific deal. The private patients get a little bit extra in relation to accommodation, standard of food and things like that, but not clinically. That model—that private-public sector collaboration—makes total sense in remote and rural Australia. There are very few examples of that in mental health—none that I can think of, to be honest.

Ms Williams—Picking up on an earlier point, I think one of the reasons why it has been so slow is the funding mechanisms in the states. Patients sitting on a trolley in the emergency department are being funded out of the acute budget and therefore it is not a mental health issue, which has a separate budget. So, in a way, they are pleased that the acute sector is caring for those patients because then it is not a budgetary problem for mental health. We need to fix that issue.

Senator MOORE—But you are brokering that at the state level in Victoria. Are you aware whether or not similar negotiations are going on in other states?

Ms Williams—We have been successful in brokering an agreement in New South Wales. Liverpool hospital actually buys beds from us.

Senator MOORE—Particularly for mental health or more widely?

Ms Williams—Specifically for mental health. And that has worked very well.

Senator MOORE—And elsewhere?

Ms Williams—We are currently in negotiations with the Tasmanian government. They are proposing to buy some mother-and-baby beds for ladies with postnatal depression. They are also looking at buying general in-patient beds as well.

Senator MOORE—Was the negotiation in New South Wales with the hospital particularly, the health board or the government? Or was it with a combination of all of them?

Ms Williams—We did it directly with the hospital and that worked very well. Whenever we approach the networks—certainly in Victoria, where we have 60 per cent of the beds—they say it is a government problem. When we go to government, they say it is a network problem. Nobody wants to own it.

Senator MOORE—I am sure, as you have explained, it has been a very long-term negotiation, but the core elements have been what you have presented to us in this paper.

Ms Williams—That is right.

Senator MOORE—We will take that up with the governments as well.

Senator SCULLION—We heard some interesting defences, as my colleague Senator Humphries has indicated, from the health insurers. To turn it the other way: they were asserting the fact that they can effectively only pay for psychiatric services when people were actually either admitted or went through the hospital system. They felt, and I think we have heard, that prevention and not necessarily waiting until you get to that point would be a lot better. They believe the services could be more effectively dealt with at that level. What do you say to those assertions? Do you agree with that submission?

Ms Williams—We strive very hard to develop alternatives to in-patient care. We have had something like a 70 per cent growth in our day programs and we have had about an 80 per cent growth in outreach, which is visiting patients in their homes. We are genuinely trying to find a substitute to in-patient care through either day patient care or home based care. We have a fight with health funds every time we try to do it. They see it as an add-on; they do not see it as a substitute. We have been able to demonstrate that the readmission rate and the length of stay for chronic patients who are cared for in outreach are significantly reduced as a result of that. There are a number of hospitals across Australia that have approval federally to provide hospital care in

the home, but the health funds will not provide a viable rate for them to provide the service in the community.

CHAIR—Is it possible to make the evidence you have available to the committee?

Ms Williams—Sure. I can provide that.

Dr Coglin—The evidence to which Ms Williams refers is a Commonwealth funded and sponsored pilot project with a very elaborate evaluation at the end of it, comparing in-patient care with intensive home based care. They took a cohort of people—so-called frequent flyers—at one of our hospitals and a number of others who had cost the fund on average, from memory, around \$80,000 in the prior year. They then treated that exact same cohort of patients for the year ahead with intensive home based treatment at an average cost to the fund—again, from memory—of around \$20,000. The saving to the payer was enormous.

As for the clinical outcomes, the satisfaction of carers—that is, psychiatrists and mental health nurses—and the satisfaction of families was at least comparable in the intensive home based model for the same patient as the outcomes in the previous year for hospital based care.

You would think this would make overwhelming sense to a funder, but one particular group of health funds I will not name declined to participate in ongoing outreach arrangements because those payments are not subject to the reinsurance pool; they are borne only by the fund that the patient belongs to and are not shared collectively by all health funds. They would rather the patient go back into the \$80,000 model of treatment and be in and out of hospital rather than use the intensive home based option, which is cheaper to the whole system.

Ms Williams—We now have some health funds that are putting a cap on our outreach services. They are saying, ‘We’re going to limit it to 20 visits a year.’ Those patients, if they relapse, will end up coming back as in-patients into hospital.

Dr Coglin—This is not based on any clinical assessment of the member; it is an administrative rule imposed by an insurer which rations the clinical care provided by psychiatric nurses, in the case of outreach, to the member.

Senator SCULLION—You talked earlier about how the health funds sometimes dissuade people from joining health funds if they are presenting with certain ailments when trying to join. Could you provide on notice some anecdotal evidence or examples, particularly in the area of mental health?

Dr Coglin—All I could take you to there is the pre-existing ailment rule, which is what you are referring to. People who have never been in a health fund who walk up and want to join are correctly required to wait certain periods of time before they can make their first claim. Those lengths of time vary according to the disease, and they are longest—in some cases up to two years—for people with pre-existing mental health disease. We would never argue that you should enjoy the full benefits from day one and just flick in and out of health fund membership according to your immediate needs, but we cannot understand, nor can we justify, the existence of pre-existing ailment rules which are more draconian on the sufferers of one kind of chronic disease than they are on sufferers of other chronic diseases.

Senator FORSHAW—Particularly when the costs may be a lot higher than for other chronic diseases for in-patient treatment.

Dr Coglin—Yes. Renal dialysis would be a perfect example.

Senator FORSHAW—You have said that the public sector system is under heavy pressure and the private sector is well equipped to handle the growing burden. Do you think there is an overall shortage of beds, if you like, for mental illness patients who need in-hospital treatment?

Ms Williams—If you aggregated the two, there probably would not be. But, looking at the public sector in isolation, there is definitely a shortage of beds.

Senator FORSHAW—I realise that, but I could not quite see how the private sector could pick up all of that shortfall, particularly given that a lot of those people would not have access to private health insurance or would have very basic cover.

Ms Williams—They would not have cover, so it would need to be paid for by another source. Not all of the patients in the public sector are going to be suitable for the private sector either. Involuntary patients are probably too high a risk. But we could certainly take the ones who were more stable, who were close to discharge or who were not deemed as involuntary.

CHAIR—We have heard in some submissions that hospitalisation does not mean much more than a secure environment and that there are no therapies or treatment other than perhaps stabilisation of medication—that is the usual term. In your hospitals typically do you use psychologists? Do you have psychotherapy and counselling? Can you tell us about that?

Ms Williams—All of our hospitals have a medical director and an allied health team, which usually comprises a psychologist, social worker and occupational therapist. In the Melbourne clinic, for example, we have 12 EFT of allied health workers; and they are required to attend a program for six hours a day.

CHAIR—‘They’ being the allied health workers or the patients?

Ms Williams—The patients attend a program for six hours a day. At some of our sites, they attend for up to eight hours a day, six days a week. So the expectation is that, if they come into hospital, they have to attend a program as part of their treatment program.

CHAIR—Does that suggest they are reluctant to do so?

Ms Williams—Some patients would want to go in for a medication adjustment, but our expectation is that they would need to attend a program at the same time.

Dr Coglin—It can also suggest they are not there for protective time out. They receive intensive programmatic therapy while they are there.

Ms Williams—The sorts of patients we are caring for are very sick, so some of our hospitals have intensive care units where they have one nurse to every one or two patients, just because they are high risk and need to be monitored very closely.

CHAIR—In your submission you compare the costs of your services with those in an emergency department. I am wondering how fair that is, given that emergency departments are filled with all sorts of amazing equipment and people running around in emergency situations. What about a comparison with other psych hospitals that are public?

Ms Williams—All we did with the emergency departments was compare the labour costs. We did not include anything else. The figure of \$1,500 a day in the submission was just labour costs for an agency nurse to care for a patient. It did not include anything else. The majority of staff caring for patients in an emergency department are usually agency nurses, and you have to pay premium for them.

CHAIR—So it is the fact that you are paying the premium for the nurse rather than efficiencies or some other measure.

Ms Williams—That is right. Because it is not a specialised area, they have to bring psychiatric nurses in to special patients in the emergency department. That usually costs about \$1,500 a day.

CHAIR—I understand. Thank you very much for your submission and for appearing before us.

Proceedings suspended from 10.34 am to 10.50 am

ROPER, Ms Catherine Elizabeth, Member, insane australia

WEBB, Mr David Robert, Member, insane australia

CHAIR—Welcome. You have lodged with the committee a submission which we have numbered 2—it must have been in very early. Do you wish to make any amendments or additions to that submission?

Mr Webb—There are no amendments. We have a few copies of documents for you and I will mention them in my opening remarks.

CHAIR—I invite you to do that and then we will go to questions. We have a relatively short time frame for this segment because we have had to fit so many submitters into the Melbourne hearings. If you could keep your statement as short as possible that would be good.

Mr Webb—With that in mind, I have written my opening remarks to be as brief and succinct as possible. I would like to acknowledge Merinda Epstein, who is part of insane australia but sitting behind us here. She has made her own submission and will be speaking to you shortly. I would like to thank you for having this inquiry and for the opportunity to appear before you today. You will see from our submission that human rights is the core issue for mental health consumers around the world and it impacts on all the terms of reference of this inquiry. At a recent conference in Italy, Benedetto Saraceno, the Director of the Mental Health and Substance Dependence at the World Health Organisation, remarked:

The violation of human rights of mental health consumers and the recognition of their role and rights as citizens are a main concern for WHO

... ..

There is a global emergency for the human rights of people suffering from mental health problems ... Human rights violations have nothing to do with poverty or limited resources ... we can see this kind of violation in rich and poor countries

... ..

... WHO does not believe in science and medicine if they are against human rights of people. WHO believe in a holistic model of care where the medical model is just one among others ... People with mental health problems are first of all citizens and therefore the full enjoyment of their citizenship should be kept as a vital framework for any medical intervention.

And finally on a specific issue Benedetto Saraceno said:

WHO would like to stress that involuntary ECT or ECT without anaesthesia should be considered unacceptable.

We would say that all involuntary treatment should be considered unacceptable. I have a copy of the full text of his talk which I would like to submit to you.

The United Nations is currently preparing a convention on the rights of people with disabilities, which includes psychosocial or mental health disabilities. The international voice of mental health consumers and the accredited NGO representing us at the UN convention is the World Network of Users and Survivors of Psychiatry. WNUSP is alarmed that the current draft of the convention discriminates against mental health consumers as somehow having different basic human rights to people with other disabilities. This discrimination against us is currently endorsed by the Australian delegation to the convention which includes representatives from the Australian Human Rights and Equal Opportunity Commission and some Australian disability organisations but not mental health consumer organisations, nor has there been adequate consultation with us, yet they dare to speak on our behalf. This is institutionalised discrimination by the Australian government against the fundamental human rights of mental health consumers.

I would like to submit another addendum to our submission that includes a statement from WNUSP and two WNUSP position papers. There is a general statement from WNUSP calling for a stop to this discrimination at the UN convention, supported by two of their position papers. The first is an advocacy note on legal capacity and the second shows that forced psychiatric treatment meets internationally defined standards of torture.

Closer to home, the Victorian government has consumer participation as one of its six key directions for mental health. The recent state budget had increases for mental health of about \$180 million over four years, but not a cent for consumer participation. This is discrimination; this is political public relations, deceiving the people of Victoria and a cruel, stigmatising slap in the face for consumers who know only too well the truth about consumer participation in this state. As a consumer representative on the ministerial advisory committee, I have advised the minister to shut down the subcommittee that I chair on consumer and carer participation, because of this blatant discrimination against consumers.

On the national level, we similarly have beyondblue, whom we heard from this morning, boasting of its consumer participation while actually discriminating against us. I have looked at their blueVoices submission to this inquiry and am again offended by their claim to represent us at all. My experience of beyondblue, over several years, is that the so-called moderator of the blueVoices network—who does not, by the way, identify as a consumer—is not a moderator at all but a censor. Beyondblue only welcomes, and very carefully selects, consumers who go along with its public relations message. It equally carefully excludes or censors dissenting voices, such as mine, that question their message, such as the need to debate the growing evidence that antidepressant drugs can induce suicidal behaviour. I can give many other examples of how beyondblue manipulates the public debate on depression, including misrepresenting its own data. With \$100 million of public funding, this is institutionalised discrimination.

Beyondblue is a good example of how discrimination against consumers and the inevitable consequence of human rights abuses arise directly from an excessive emphasis on the medical model of mental health, as detailed in our submission. There is a medical colonisation of mental health, which some are calling the ‘sickness industry’ or ‘disease mongering’. Beyondblue is part of this. The ‘medicalisation’ of mental health, supported by legislation that denies us our citizenship, is used to justify the most serious human rights violations of forced psychiatric treatment through claims that it is ‘for our own good’. Please remember the stolen generation when you hear this phrase. Forced treatment and the threat of force, more than anything else, are the foundations of the culture of fear and intimidation that poisons our psychiatric wards. Human

rights abuses are not accidents but inevitable in such a culture. Forced treatment is killing more people than it saves.

In conclusion, mental health consumers have fewer rights and fewer protections of our rights than those in the criminal justice system have—all without us ever committing any crime—with the inevitable consequence of serious human rights violations, and all in the name of a fundamentally flawed medical model that this is ‘for our own good’, which really relies on the assumption that we are legally incompetent. I will now hand over to Cath, who will talk about three things that insane is asking for.

Ms Roper—Firstly, mental health is a social issue, not just a health issue. I have just come back from New Zealand, where consumers were involved at a governance level through district health boards. Consumers have government contracts, for example, to manage national antidiscrimination campaigns through their own districts. Through trusts, consumers operate peer support services, education services and advocacy services.

Here in Australia, we have had policies for over 10 years in relation to consumer involvement in policy, service planning and delivery, education in the mental health sector for practitioners and monitoring and evaluation of services. We are languishing here; we have not made any real inroads into being able to support these policies. We cannot do that without the structures, the commitment and the dollars to make it happen. We are not just one group of stakeholders; we are the stakeholders. We are not after a democratic process; we are after affirmative action. We should no longer be talking about consumer participation. Consumer perspective is absolutely fundamental to everything that goes on in mental health. This is about our right to self-determination, having some control of how money is spent and being in positions of authority.

We do not want to see more money being spent exclusively on more beds and more medical responses. We do not think that the present system is working. We want to see money invested in consumer recovery and consumer operated services—true asylum and nurturing places with enough time to heal, and housing that is safe and suits our needs. We are interested to know the total amount being spent on consumer operated services in the nation.

So what we want? We want the creation of a legislated body. You cannot have the existence of separate legislation taking away our civil and human rights without a concomitant watchdog. You cannot take away rights without providing advocacy as needed. An independent mental health rights commission would be able to receive complaints from all sources and receive complaints data from all sources. It would be able to be independent and empowered to make governments and services accountable for the services that are provided to the community. It would be empowered to undertake investigations, make policy recommendations and report directly to parliament, and it should have the capacity to provide proper legal advocacy.

We also want a Senate standing committee to hear abuse testimonials. We have an appendix on this process which has just begun in New Zealand, a very similar process called the Confidential Forum, and we have information about that. This is very necessary because we need a structure in which people can talk about the experiences that they have had at the hands of services whether it be 30 years ago or last week. We need a structure.

Finally, we need proper funding for consumer operated services. We want to see the creation of a mental health consumer perspective studies centre. We want to see funds directed towards peer advocacy and peer support to support our networks. We are doing this in our own time and with no money and we need dollars for consumer operated services. Thank you for your attention.

CHAIR—It is interesting that you referred to New Zealand. The committee met with some commissioners from the Mental Health Commission just a week or so ago. Is that effectively what you are recommending—a commission similar to New Zealand's?

Ms Roper—Their function is slightly different. They have an expanded role. They have produced some terrific things—videos and so on—and they have taken up the antidiscrimination campaign really successfully there. We are also looking for a body that can investigate complaints, and I think that the commission in New Zealand has a slightly different function. We are looking for something that can offset the fact that our rights are taken away under legislation. There have to be proper checks and balances. At the moment complaints data in Victoria, for example, is not aggregated, so although it may come from many different sources there is no overarching body that can keep track of what is going on, what the problems are and how to fix them.

CHAIR—So you are talking about a New Zealand type commission plus an ombudsman's role, effectively?

Ms Roper—It is more like an ombudsman's role, yes, but we also think it should include advocacy and the capacity to do things like New Zealand have done. They have produced recovery competencies and things like that. It is very much an educational role and I think that is an important feature too.

Senator HUMPHRIES—You make a case in your submission for an inquiry or a commission to investigate mental health human rights abuses in Australia. But the submission does not relate any cases of abuse. It does not give any case studies or mention any incidence, reported or unreported, of those sorts of abuses. In fact the tenor of most submissions to the committee to date in terms of abuses in relation to mental health has been a failure to get access to the system, a failure to get into the system, rather than abuse of people within the system. So there is a lack of evidence about this. Are you able to produce for us case studies with the names changed or removed, if necessary, that help us to understand what these abuses are?

Ms Roper—Partly, there is a lack of evidence because we have not had this opportunity. I can tell you that the Victorian Mental Illness Awareness Council are coming across examples like this every day. I cannot speak for them; that is not the role I have. But as an example I can tell you that I was sexually assaulted by a charge nurse when I was hospitalised and I have never had the opportunity to talk about that. I know that there are many other people that I have talked to, both as an in-patient and working with consumers, who have stories of abuse to tell.

Senator HUMPHRIES—My point is that we are not hearing those stories. It would be useful if those stories could be compiled and given to us. If you have that kind of evidence, I would be interested in seeing it and having it put before the committee. As I said, it could be with

identifying information removed but give examples of the kinds of abuses that you are talking about.

Mr Webb—Part of the problem with that evidence not being available is precisely because we do not have the opportunity to tell our stories. Cath mentioned the Victorian Mental Awareness Council, whom I think you are hearing from this afternoon. In some ways we are better off than other states. Isabell Collins has plenty of stories on file, and I think she will be able to tell you some of them. We hear these stories regularly. In Europe there is a group called *Le Mouvement Les Sans Voix*—my French pronunciation is not too good—which means the voiceless movement. Our submission is first and foremost about giving consumers voices. I am confident that I can briefly mention Merinda. I have heard her say publicly that her experience of hospitalisation has been that she has required counselling afterwards because of the trauma she experienced in the services. We hear these stories time and again. We get very little opportunity to bring them to the public's attention, which is why we think this inquiry is so vitally important. We need consumer organisations where our voice can be expressed.

Senator HUMPHRIES—You mention in your submission the issue you have with psychiatry in Australia. You have argued that services have been denied to people because they fail to meet diagnostic criteria. I think that is a very good point. I have some agreement with that point. But you seem to go beyond that. You have said already today that treatment should not be offered or provided to people unless they consent. Although I think you have brought out in this submission the case of people with a degree of self-awareness who are mentally ill and who are in a position to contribute to an understanding of what their treatment regime should be, surely it is also the case that there are many people who simply are not in a position to offer consent because of a lack of awareness of what is happening to them because of their mental condition. For them, it is still vital that the system provides treatment, involuntary if necessary, that deals with their mental illness.

Mr Webb—This is really a popular myth that is promoted on the basis of the medical model of biological psychiatry, which dominates the landscape at the moment. I also remind you of the stolen generation. This is precisely the same argument that was used to remove Aboriginal children from their parents. It is not an argument. The woman leading the delegation for WNUSP on the UN convention is an American human rights lawyer. That is why I have tabled that note on legal capacity. It goes to self-determination. For some reason, people with mental health issues, or psychosocial disabilities, as they are sometimes called, are judged to have less legal capacity than other people. The legal arguments, the ethical arguments and, certainly, the medical arguments just do not stand up.

On a personal level, in terms of my experience—and my involvement here is through my history of suicide attempts—I note Jeff Kennett talked about stigmatisation as a huge obstacle to our need to get people to come forward. Because I speak publicly about my history of suicidality, I do get asked: what would you say to someone who was feeling suicidal? I cannot possibly recommend that someone who is feeling suicidal disclose their feelings to someone who is then going to assault them—and that is what happens. If you talk about suicidal feelings, it is quite likely that you are going to be locked up and then you will have quite invasive treatments imposed on you against your wishes. We find that people are absconding from our mental health services, whether they be voluntary or involuntary, specifically to go and kill themselves. There is quite clear data about that but no-one is asking the question: what is

happening in these services that people are escaping to go and kill themselves? To me it is very understandable: if you present to someone seeking help—perhaps your last grasp at staying alive—and you find yourself being assaulted, it is to be expected that you will flee that situation.

Ms Roper—My answer to that would be, in the terms of your question, that I would always have been the person who had ‘no insight’—that is the other term that is used. I had 13 hospitalisations—all of which were involuntary—yet I cannot look back and say that those were healthy for me. There was extremely traumatic forced treatment involved in each of those hospitalisations.

Senator HUMPHRIES—I suppose the problem for us is that we will undoubtedly receive evidence from psychiatrists that says that for some people that is the only form of treatment that is appropriate. We need to act on the basis of evidence and we would need evidence that that is wrong. You have asserted that it is wrong but, in a sense, how can you convince us? What can you offer us to show that in every case it is not appropriate to provide treatment unless there is consent? I ask that because we will be told by psychiatrists that some people are not in a position to give that consent.

Ms Roper—I could never argue that forcing something on somebody against their will is justifiable. It is on philosophical grounds.

Senator HUMPHRIES—Even when a person, it could be argued, does not have an informed will because of their state of mental distress?

Ms Roper—On philosophical grounds I cannot justify that.

Mr Webb—And also on the practical grounds that I just described. The demand for evidence that you are putting before us is another aspect of the discrimination. As to my other work—my major work—I am about to complete a PhD at Victoria University on the issue of the lived experience of suicidality. What is very clear from my own research is that there is a systematic exclusion of what I now call the ‘first-person voice’ or ‘first-person data’—the subjective lived experience of a whole range of mental health issues. My research focuses on suicidality. For instance, if you look at the submission from Suicide Prevention Australia you see they have taken this up and have identified that one of the areas in research that is most lacking is the subjective lived experience of a whole range of mental health issues.

This medical demand for evidence is about only evidence according to the medical criteria of what constitutes valid evidence. For instance, the randomised control trial is the gold standard as to what constitutes valid evidence. If those are your only criteria for what is valid evidence, you are not going to hear from people like Cath and me. You are not going to hear the first-person voice, which is other vital evidence that needs to be heard if we are to understand what we are dealing with here. We are calling here for that voice to be heard. So another form of institutionalised discrimination against mental health consumers occurs in the research community, which uses the medical criteria as to what is valid evidence to silence us.

CHAIR—Continuing on that point, what is your preferred model? If someone who is intending to suicide is presented and it is the opinion either of those people who are with them or

of medical experts in various fields that medication, for instance, is necessary, what do you think would be a way of dealing with that which avoids this problem of involuntary treatment?

Mr Webb—I once heard a story about someone who asked an Aboriginal elder what their community does in their traditional culture for someone who experiences what our society call psychosis. The answer was quite brilliant, and it is another example that shows we are not connecting with the Indigenous wisdom that we have. The answer was, ‘We do two things: we let them have it and we do not leave them alone.’ I think the proposals that Cath has outlined—recovery orientated services and genuine asylum—are the sorts of things that allow people to have these difficult experiences but in safety with people who can respect that and share that with them. It is not about fixing it; it is not about controlling it or suppressing it. I am not a religious person, but I love this phrase: to bear witness. Another one is the notion of pastoral care—to be with people during these difficult times, to hear what they are saying and struggling with. It is, in fact, what we do all the time anyway through our work and through, for instance, the Victorian Mental Illness Awareness Council. I am currently the chair of VMIAC. I know you are also receiving submissions from other people, such as Paris Aristotle who is appearing this afternoon with the victims of trauma and torture group, and people in the drug and alcohol recovery areas.

All of those sectors, if you like, are encountering people who are having suicidal experiences, thoughts and feelings. It is quite common. They do not resort to violence to deal with that. They do things like bear witness and share. When I am asked what I would answer to someone who is feeling suicidal, I would say, based on my research arising from my own experience, first and foremost to respect those feelings. Respect them as legitimate, valid, human experiences. But then I say, ‘And distinguish between respecting them and feeling the urge to act upon them.’ That is a respectful response; it is how I always respond, and I do get approached by people who are feeling suicidal. I do not have the authority to lock them up, and I cannot recommend they go to a place that will do that to them. I am more concerned that, if someone is feeling suicidal, if I suggested they go and see a psychiatrist that could very easily push them over the edge. We need a human response to this, not a medical one.

CHAIR—And if that human response does not work, would you also advocate any kind of restraint against taking action that would cause someone to lose their life?

Mr Webb—There is an important distinction to be made between involuntary treatment and involuntary detention. For me, involuntary treatment has always been totally unacceptable. It is an assault, and a violent assault. The treatments we are talking about radically change your personality—sometimes permanently. For that to be imposed upon you against your wishes is a cruel and vicious assault, and some people are now talking about it as torture. In terms of involuntary detention, Mary O’Hagan, a mental health commissioner from New Zealand, helped me to see the distinction. Involuntary detention controls where you are; involuntary treatment controls who you are. It is a really important and significant distinction. For a while I thought that possibly physically detaining someone was a legitimate thing to do, but I have come to the conclusion that it actually does more harm than good. People will say that these involuntary responses to suicidal feelings are necessary to save lives. I say that it is killing more people than it is saving. We have to accept that it is unlikely that we are ever going to get the suicide toll down to zero.

CHAIR—So you accept the inevitability that some people who wish to end their lives will do so. Is that what you are saying?

Mr Webb—The other reality of course is that we cannot stop them. In the end, we cannot stop them.

CHAIR—I understand.

Senator FORSHAW—You are putting this to us from the perspective of consumers. I appreciate what you are saying and I do not think any of us doubt that there is scope for abuse and that abuses have occurred; the things that happened at Chelmsford Hospital and in other institutions in years gone by come to mind. But would you concede that there are also consumers who have a different but legitimate point of view? That is, they will say of the treatment they received, if it was involuntary, that their psychiatrist was of great assistance, as was the medication that they received. I have spoken to people in that situation. I know people in that situation, and I have known them over many years. I think all of us to some degree or another have come across people expressing that view, as we probably have come across people expressing the same sort of view you have. You speak very forcefully in support of your view about consumers. My concern is that maybe that puts forward a position that this is a blanket, right across the board view. Do you accept that there is a place for your sorts of views as well as for the views of those who say the involuntary system has to be there and that it works for some, or many? Somehow we have to deal with issues of abuse and the violation of fundamental human rights co-existing with the need, in certain situations, for people to be hospitalised involuntarily. Can you accept that that is a legitimate view?

Ms Roper—I can give a partial answer to that: we do not have any alternatives. This is the problem. We have only a public health system in which, percentage wise—at least in Victoria—people are largely treated involuntarily.

Senator FORSHAW—Some people say that the alternative is a situation where a person may have to be hospitalised and treated involuntarily with medication. We had the bad old days of intensive shock treatment, and I know it must still occur, but at least a lot of those practices have been identified and dealt with. What really needs to happen is that, when people come back out into the community, back to their family or whatever, the services to help them cope are there. Then there is a combination of intensive hospitalisation treatment and good services in the community that will work for many people. You are painting a picture where they just go into hospital and may try to get out or commit suicide because the system does not work for them.

Mr Webb—I do not think we are actually painting that picture. I do hear consumers say what you are saying, that if it were not for the involuntary treatment they received they would be dead today, and I respect consumers that say that.

Senator FORSHAW—It may not be that they are not dead; they may feel that they can live a better life—that they can cope with their illness in a more stable way.

Mr Webb—I am talking about consumers who speak appreciatively of the involuntary treatment that they received. I ask those people two questions: firstly, do they agree that such violent treatments are also killing people; and, secondly, is there anything else that they can

think of that might have been able to help them at the time they received the involuntary treatment? So far the answer to both those questions has always been yes.

I need to add that I have spoken to only a few people who have received involuntary treatment—and I have heard one or two stories along the lines that you suggest. Although such cases are often quoted, they are very rare. It is not hard to find people who will talk agonisingly of the abuses they have received, but the few people who will acknowledge they have received involuntary treatment—which I respect—are fairly rare.

The second and probably even more important point, which is the real guts of our submission, is: let us hear from those people. You should hear from all of us. We do not want to try to dominate the consumer argument with just one point of view. We are a community with a wide range of different views. We compare ourselves to the women's movement or the gay movement. There are many voices within our movement and they all need to be heard. That is not occurring at the moment. Instead, groups like *beyondblue*, *insane australia* and the Mental Health Council of Australia choose the consumers that go along with what they say. If this society truly wants to learn about the experience of madness, as it is lived by people in this culture, it needs to hear from us. To do that, we need our organisations, our forums, our web sites, our newsletters and our conferences so that our voices can be heard. We do not have those at the moment. There is a systematic silencing of us. Look at the funding given to the Australian Mental Health Consumer Network. The total funding for our national voice equates to about half of your salary. That is the institutional discrimination that, as stated in our submission, needs to be addressed.

CHAIR—Would you like to say anything else to the committee before we finish this session?

Mr Webb—No. Thank you for this opportunity.

CHAIR—Thank you very much for appearing.

[11.28 am]

EPSTEIN, Ms Merinda Jane, Private capacity

CHAIR—Welcome. You have given us a joint submission, which we have numbered 207, and now you have provided us with a slightly amended version of that submission.

Ms Epstein—Yes. That version went into the secretariat, but somehow part of it did not get through to you.

CHAIR—Do you need to make any further amendments or additions to that submission?

Ms Epstein—No.

CHAIR—I invite you to make a brief opening statement, after which we will go to questions.

Ms Epstein—Thank you for inviting me to present to you today. I have drafted my presentation because it includes personal testimony as well as political argument and my reading of it will be made easier. I also apologise that it may take a little longer than five minutes, so I will try to read quickly.

Firstly, I want to support insane australia's presentation made by Cath and David. The first half of my written submission describes, as best I can, what I believe to be the current state of affairs in regard to consumer participation at a national level. I also make some recommendations, including making available essential funding for a national consumer perspective studies centre to be annexed to an educational institution somewhere in Australia.

There is so much to say about unconditional and untokenistic consumer participation and consumer run services, but I have chosen today to concentrate on the second half of my submission and, particularly, to concentrate on borderline personality disorder. My interest in this area came originally from my own personal experience in the Victorian mental health system, when my diagnosis was changed from a psychotic illness to a borderline personality disorder. The change in attitude towards me after this was palpable. Whilst the system believed that I had a proper mental illness, I was not treated well. But at least I was treated and an attempt was made to take me seriously and to understand my distress and to help me. Crisis teams usually came, and their approach to me was serious and sometimes respectful.

After my diagnosis had been changed to borderline personality disorder, all this abruptly ceased. I was now charged with deliberately upsetting other patients, stacking it on, attention seeking, acting out and all manner of unfair and inaccurate things. After having a borderline personality disorder diagnosis for a couple of years, I had an opportunity to view my records under freedom of information legislation. I could not believe that other human beings could write the sorts of defamatory things that now had appeared in my file. I still live in fear of my medical records. It is imperative now that I avoid any hospital in Melbourne that I attended during that time. I have no confidence that, if I were to present for emergency treatment, professionals would have any capacity to view a present medical problem, either physical or

psychiatric, from outside a now discredited diagnosis of borderline personality disorder. This has real implications when we start talking about medical records being more widely available between different states and territories.

As my present psychiatrist put it a couple of weeks ago, ‘You were diagnosed with having schizophrenia but accused of having borderline.’ She has now diagnosed me with bipolar affective disorder or manic depression and post-traumatic stress disorder, which I developed as a direct result of being assaulted while in a psychiatric hospital. With bipolar affective disorder under my belt, I am back on the right side of the ledger, as it is another diagnosis that, like schizophrenia, is considered legitimate. This is crazy. At present, we have good and bad mental illness and the baddies are systematically refused services, vilified and deemed not to be serious, despite overwhelming evidence to the contrary. The worst of the baddies is borderline personality disorder.

I have never had an experience in an acute psychiatric hospital where I have not needed intensive counselling afterwards to recover from that hospital experience. You might like to read the poem I wrote after an admission, which I have appended to the submission. I have been assaulted by other patients. I have been patronised, infantilised and treated as though I was deliberately manipulating clinicians. Recently I was discussing my bad track record with my psychiatrist and we both agreed that most of the damage was done during the years that the system thought and the records said I had a borderline personality disorder. She commented that the problem with psychiatric hospitals is that too often people go in with one diagnosis and come out with two, because what they have experienced has traumatised them so badly. She told me that she has treated many patients who were recovering from post-hospital shock, especially after involuntarily but also after voluntary admissions to public psychiatric hospitals. We agreed that, for a number of reasons that are embedded in some women’s histories, incidents of hospital assault and terror were more likely to happen to those labelled as having a borderline personality disorder than any other single diagnosis.

Borderline personality disorder is not considered to be an enduring and severe mental illness in any state or territory in Australia, despite the fact that the suicide rate for it is about the same as for schizophrenia and its rate of prevalence being nearly identical to low-prevalence psychotic disorders such as schizophrenia and bipolar affective disorder. If people were asked to name a devastating mental illness, very few would identify borderline personality disorder. Despite the number affected by it, it is largely a hidden scourge—and, for various political reasons to do with the system’s fear of inundation, this secrecy is encouraged. The definition of ‘serious’ has more to do with protecting the public from danger—read ‘psychotic men’—and with political pressure by influential organisations such as SANE than with a genuine attempt to understand what constitutes ‘serious’ for those who experience the distress.

One of the by-products of the medicalisation of medical illness is that it illegitimises the genuine distress of people whose psychiatric anguish does not respond to medical drugs. The mental health industry often uses the language of ‘just behavioural’ as a cop out for not taking responsibility in these circumstances. This is exactly what happened to Cornelia Rau. Her distress and failure to cope being seen as just behavioural, society and its institutions justified the treatment she was receiving at Baxter. It was only at the point she was diagnosed with schizophrenia that the public outrage burst into the press. Frankly, that is discriminatory.

There is general agreement that people with a borderline personality disorder do not do well in acute hospital settings; however, their needs are just as genuine as those of people who sometimes need in-patient stays. An increase in beds will do nothing to relieve the problems experienced by people with such a disorder. They need ongoing intensive psychotherapy and reliable support and care in community settings, not beds. This costs money, which must be budgeted for. The public mental health sector often is not set up to provide these things any more, with rotating psychiatrists and allied health practitioners being diverted off to become case managers.

Victoria has Spectrum, the only state-wide borderline personality disorder service in Australia. Even with Spectrum in place, Victoria falls well short of meeting the need for services. This is partly because Spectrum can take on only clients who already have a case manager in their local public mental health service. However, as a borderline personality disorder is not considered to be a serious mental illness, people diagnosed with it are often refused case managers. This is a ridiculous catch 22 situation.

People with a borderline personality disorder account for a large percentage of people who, after self-harming, present to casualty departments. This is a major problem in all states and territories. This is not because such people are bad and demanding, and they are not attention seeking. People with this disorder usually are not trying to kill themselves when they self-harm; rather, paradoxically, it is the only way they feel safe enough to keep living. This precarious survival strategy nearly always has deep historical roots. These people need to be treated quite differently from those who have tried to kill themselves; however, that rarely happens. In most states, people who come into casualty departments after self-cutting, overdosing or burning frequently are derogatorily told off, reluctantly patched up and, with their feelings of self-worth in even greater tatters, dismissed back out on to the streets with absolutely no follow-up or support.

I am submitting a letter from the *Guardian* in which one clinician from accident and emergency vents her spleen about people who self-harm and then turn up in casualty. This letter can express better than I can the dreadful stand-off that so often tatters relationships in emergency departments. If emergency departments do try to provide follow-up, psychiatric crisis teams in states and territories have instructions that people with a borderline personality disorder are of the lowest priority. Services are again refused because the distress is judged to be not 'mental illness', as defined by state mental health legislation. In this way, legislation that has been drafted carefully in an attempt to protect the human rights of people who are not demonstrably psychotic gets used for gatekeeping purposes for which it was not designed.

There are other things that must be understood. About 75 per cent of those who are diagnosed as having a borderline personality disorder are women and 80 to 90 per cent have a history of abuse and/or neglect; and people who have been diagnosed with a borderline personality disorder are significantly more likely to become victims of rape and violence as adults than the general population.

There are many women in prison systems with a diagnosis of borderline personality disorder. Many of these women regularly self-harm. If we had a mental health system which prioritised all serious emotional distress, regardless of its aetiology, and could see beyond the short-sighted emphasis on psychotic illness, we could avoid many women ending up in prison. It would

circumvent unnecessarily forcing women into a miserable recidivist lifestyle where self-harm becomes the *modus operandi*, and it would save states and territories a lot of money.

You cannot get rid of people with borderline personality disorder by simply calling them a pest and defining mental illness in such a way that they cease to exist. Important epidemiological studies which were undertaken by the Commonwealth as part of the second National Mental Health Strategy in the late 1990s did just that. There is no more alarming evidence of discrimination within the mental health system than this. Service needs and state service planning since this time have all been based on the false premise of these studies. Since the serious mental illness rhetoric of the first National Mental Health Strategy appeared in 1993, we have lost a whole generation of psychotherapists from the public mental health system throughout Australia. People with skills in self-psychology, milieu therapy and dialectical behaviour therapy, which are the three evidence based successful treatments currently available for borderline personality disorder, are almost nonexistent in some states and territories and adequate in none.

The first need of people with borderline personality disorder is a system of community supports which is reliable and consistent. Chaotic internally, the last thing these women need is to be confronted by a chaotic and unpredictable mental health system. The underfunded service system confusion which exists in public mental health sectors throughout Australia at the present time is unhelpful for all people but particularly dangerous for people experiencing life through the eyes of childhood abuse and the disturbing and often debilitating adult traits of borderline personality disorder. It is a horrible, damning diagnosis which needs a new name because 'borderline' is now too tainted. Some of this needs to be driven by a change in emphasis and priority at the government policy level. The national mental health strategies have so far been overwhelmingly silent in this regard. However, it also needs to be funded at the state and territory level because a change in rhetoric will not change anything if it is not backed up by resources.

CHAIR—Is a change of name enough to do the trick, as it were?

Ms Epstein—An American psychiatrist who is very interested in this issue calls it 'complex post-traumatic stress disorder' to try to put the emphasis on the fact that the majority of these women have abuse histories. We generally think that that is a bit clumsy but better than 'borderline'. I have been organising things with consumers where they have literally said to me, 'You can tell them I've been diagnosed with schizophrenia, if I talk publicly, but don't tell them I have borderline personality disorder.' The stigma even within the consumer movement is much greater around this particular diagnosis.

CHAIR—You said that Spectrum is the only service for borderline. Who works there? Are they psychologists or psychiatrists? Does the psychiatric profession acknowledge what you have just told the committee?

Ms Epstein—Yes. Spectrum is a state-wide service. It provides very limited serving of clients; it actually provides secondary support to other services which are trying to deal with people with this particular diagnosis. It is great that we have a Spectrum. We worked very hard to get a Spectrum, because up until the time that it was funded there was absolutely nothing in Victoria at all. When I talk to my consumer colleagues in other states, I am told that in Sydney

there is one service which is around self-psychology. A well-known psychiatrist in Sydney has set that up, but that is all they have in New South Wales. We are very limited. In the other states there is absolutely nothing.

CHAIR—Did you say ‘self-psychology’?

Ms Epstein—It is called self-psychology. It is just a name, but it is a form of psychotherapy. Russell Meares, who I believe is Ainslie Meares’s son, has developed this particular method, and it is a really good, evidenced based treatment. They are promoting it in Sydney, so that is good. It is starting to make a little inroad, but there is a long way to go.

CHAIR—How widespread is the knowledge of this disorder amongst general practitioners and amongst psychologists and psychiatrists?

Ms Epstein—I reckon in every aspect knowledge of psychotic illness is about 15 years ahead—general practitioners and other people would know as much about borderline personality disorder today as they probably knew about psychotic illness 15 years ago.

CHAIR—Which is not a great deal?

Ms Epstein—Which is absolutely not enough. People find it frightening because they cannot immediately understand, it does not make sense medically, and they cannot give someone a drug. That does not work. It needs intensive therapy. Mostly people just vilify women with this illness and send them off into the streets, which is tragic.

CHAIR—Did you not indicate earlier that you are on some sort of medication for this disorder?

Ms Epstein—Yes. What I need to say about diagnosis is important. I have had 15 different diagnoses. The latest one is bipolar, and I am on medication for that. My psychiatrist is very angry that I ever got diagnosed with borderline personality disorder. She says that she cannot see any sign that that had any accuracy whatsoever. I became interested in it because of the way I was treated when I got that label. I did not actually have it. I could not believe how badly I was treated, and that was directly to do with that diagnosis.

CHAIR—I understand.

Senator HUMPHRIES—What you have described with respect to the treatment of people with borderline personality disorder seems to suggest a major problem with the way psychiatry is taught in medical schools or schools of psychiatry, the way it is practised and the culture of psychiatry in Australia. It is difficult for a Senate committee to change that, even if it makes a recommendation that it should change, because psychiatrists will say, ‘This is a clinical decision, not a decision for laypeople.’ What practically should the profession be doing to confront the need for better knowledge about this? Should there be some kind of program of engaging with people who have this illness so they get more exposure to what is going on, for example?

Ms Epstein—I think that is a very good idea. One of the things I have been thinking about is that, now that we have Spectrum, for example, it would be really good to have money going into

that organisation that enabled them to do some public education around this stuff. It would be good if they could have a boosted budget—

Senator HUMPHRIES—Or education of psychiatrists, more specifically.

Ms Epstein—to educate psychiatrists. There is also a very big need to educate psych nurses. I will give you a little example. We were taken for a walk when I was in an acute setting with this diagnosis hanging over me. As you can see, I have a disability. The psych nurse told me to stop putting it on, walk properly and catch up with the others. I know it is little. She probably would not have said that if I had one of the good diagnoses like schizophrenia or bipolar. It was aimed at me because that label brings with it a total lack of trust by others in anything you say from that point on, even something as obvious as a straight leg.

Senator HUMPHRIES—In the other part of your submission, which we have not spoken about today, you talked about the value of the national community advisory group, the benefits of that process and how it has ultimately been subsumed into the Mental Health Council. What would you say were the achievements of the NCAG while it was in existence?

Ms Epstein—I think that it was the first time we had consumers and family carers attending everything where decisions were being made at a national level. So a whole lot of groups of people who were used to having a lot of power and only seeing consumers as patients suddenly saw us as equal decision makers in those situations. Even though we often could not change what was happening because we did not have critical mass, we were there, and that caused a huge change in thinking by some of the most powerful groups in mental health in Australia at that stage.

And I do not think the NCAG model would have lasted anyway, because it was something very special straight after the Burdekin report, when people were really conscious of the stories that consumers and carers had told Burdekin during that inquiry. It was very interesting that when NCAG was set up, because it had two representatives from each state, nearly all the states sent carers. They ended up with a really big problem: the consumers got furious because they were totally outnumbered. When I was asked to sit on NCAG with Simon Champ, it was to have two extra consumers just to boost our numbers so that we would not have scenes at committee meetings. We have moved a long way from that. With all my reservations about the Mental Health Council, I do think we have moved away significantly from what it was like when NCAG was first set up.

One of my problems with the Mental Health Council is that I am not 100 per cent sure what they are doing. I have heard rumours that they are having a look at the constitution. I was involved in writing the constitution and we were really careful to make sure that the executive would always have consumer representation. I do not know this but I have heard rumours that that is being questioned at the moment. If that were to happen, it would be a tragedy.

Senator WEBBER—I was having another look at some of your cartoons today—some of them are very clever. Firstly, I would like to thank you and the previous witnesses for having the courage to share your stories with us. It is pretty confronting for us to hear what has happened to you; I can only begin to imagine what it must be like for you to go through the trauma and treatment that you have.

In terms of your role as a consumer representative—this question would probably apply equally to Mr Webb and Ms Roper—it occurs to me that because of the stigma that a number of mental illnesses have, particularly borderline personality disorders but also a lot of the others, perhaps some of the reluctance to involve the consumer voice is because we find it too confronting and all a bit scary and we do not know how consumers, the people suffering from some form of mental illness, are going to behave on any one day. We know what people in wheelchairs look like; we know what their issues in terms of access are going to be. We find that a lot more straightforward than dealing with people who look like us but who we are not quite sure about in terms of how they are going to behave. Do you sense that reluctance or have I misread that?

Ms Epstein—I am absolutely sure you are right, because it is in many ways an invisible disability. There is fear in that people do not know how someone will behave—that is about behaviour. But they also fear that they will say the wrong thing or offend accidentally. With somebody in a wheelchair, the things you should steer clear of in terms of trying to make decisions with that person are more obvious. I have lots of jokes about this because, as you can see from my cartoons, I think that joking and picking up what we call the ‘consumer language’ is a really important way of getting past these sorts of positions which people cannot move from. I often call myself a ‘high-profile nut case’. I do that quite deliberately, but sometimes when people who are not used to consumer activism hear it they are horrified.

It is very interesting in terms of antidiscrimination and antistigma. I have often been on the podium with Barbara Hocking from SANE. Usually I go first, which is one of the things about being a consumer—they ask you to speak first. We need to reclaim this language. We need to call ourselves ‘batty’; Cath has a wonderful T-shirt about ‘batty’ and ‘nut case’. We need to reclaim that language and make it not scary. Then Barbara gets on to speak and from a non-consumer perspective says, ‘We need to get rid of all these horrible words like ‘nut case’. Both of us are trying to do the same thing in totally opposite ways. That is where the consumer perspective is so vital. If we just rely on people who read it from a non-consumer perspective, I think that we will not make inroads into discrimination as quickly as we will if consumers start to challenge it in unorthodox ways through such things as cartoons and language. I am not sure that I answered your question.

Senator WEBBER—Yes, you have.

CHAIR—Thank you very much for appearing before us today, Ms Epstein. We will be talking with you again with another group tomorrow. I share Senator Webber’s sentiments in terms of knowing that it can be a daunting experience to come before the committee in this way, so I thank you for doing that. I also thank you for the cartoons. We may come back and ask you whether we can use them in the report.

[11.56 am]

ARISTOTLE, Mr Paris, Executive Member, Forum of Australian Services for Survivors of Torture and Trauma and Director, Victorian Foundation for Survivors of Torture

AROCHE, Mr Jorge, Executive Member, Forum of Australian Services for Survivors of Torture and Trauma and Executive Director, Service for the Treatment and Rehabilitation of Torture and Trauma Survivors

KAPLAN, Dr Ida, Manager, Direct Services, Victorian Foundation for Survivors of Torture and Member, Forum of Australian Services for Survivors of Torture and Trauma

CHAIR—Welcome. You have lodged with the committee submission No. 397. Do you wish to make any amendments to that document or additions to it?

Mr Aristotle—We have prepared some supplementary information to go with that submission and I have copies here for members.

CHAIR—Those supplementary submissions are now received as evidence.

Mr Aristotle—It is primarily background material elaborating on some of the specific issues.

CHAIR—I now invite you to make a brief opening statement, after which we will go to questions.

Mr Aristotle—Thanks very much for the invitation to appear here today. It is an area of great importance to us, naturally, and the opportunity to be able to talk about the needs of our client group in particular is fairly rare. It is a terrific thing that you are actually conducting this sort of inquiry and providing these opportunities for us, so thank you very much for that.

Some of the pressures that the agencies have been under in recent months are partly the reason you have a couple of separate documents rather than having received our evidence in the one submission. We are also primarily a direct service agency, so most of our work and energy is taken up with casework. That has a big impact on our ability to prepare material for this. That is not a complete excuse—it is just to give you some reasoning for why you have got two separate bits of information.

We are really keen to get into having a discussion. Our experience is always that it is better to work through these issues based on the questions people have, because we can virtually elaborate on all of the material through that sort of process. In the supplementary information on page 1, there are some key recommendations which are consistent with the original submission. But I just point out that those broad key recommendations or areas to focus on are not all that we believe is necessary to deal with these issues. They capture in broad terms the key elements where we think, if there were some progress made at a federal and state level, there would be substantial improvements in the mental health of refugees and survivors of torture and their

ability to settle in Australia. I do not want to talk to it anymore, if that is okay. We would just like to go into questions and into a dialogue.

CHAIR—Dr Kaplan, do you wish to add anything to that?

Dr Kaplan—No.

Senator HUMPHRIES—I firstly want to ask about the key differences between mental illness in the community generally and mental illness in the sorts of clients you deal with. It might be an overgeneralisation to suggest that a lot of mental illnesses are genetic or hereditary; that may or may not be the case, so I will not go into that question. I assume that a large amount of the illness you deal with is caused by the environmental circumstances the people have come from. If that is true, how has that led to differences in the nature of the treatment regimes that are necessary for these people?

Mr Aristotle—It is true that the primary generator of mental illness or mental health difficulties for our clients is the nature of their pre-arrival experience. Most have survived wars and have often lived deprived of services for very long periods of time in refugee camps. The refugee camps are often extremely dangerous. Lots of violence takes place in camps. Women and children are often subjected to rape and abuse inside camps. For us there is a prevalence of actual experience of torture where people have been detained for a long or short period of time and directly tortured physically and psychologically or where the level of security inside camps or inside a particular region is such that paramilitary groups or government military groups are able to reign with a fairly free hand and violate people's human rights on a regular and routine basis. They are the principal factors that generate the trauma and, as a consequence, the psychological difficulties that people experience.

Post-traumatic stress disorder, anxiety and depressive disorders are very common features in our assessment of our clients. One of the really profound issues is the impact of loss and grief. Most refugee families have been fragmented in some way. Many will have directly witnessed the death of family members, loved ones and friends. Oftentimes they are separated from family. Some are left behind and others have been able to make it to Australia either through our humanitarian program or as asylum seekers. Separation, loss and grief feed into a profound sense of guilt. These factors complicate people's ability to seek assistance, to believe they are worthy of that assistance or to believe that that assistance would be forthcoming even if they did seek it. Layered over the guilt and the extreme traumatic experiences are the different cultural dimensions—the completely different frames of reference between their own lives in their countries of origin and how we live and operate in Australia, and all the adjustment difficulties that presents. Their mental illnesses are certainly not organic or inherited but much more a feature of the environments from which they have fled.

Mr Aroche—One important thing to point out is that refugees are subject to mental health disorders just like the general population, and therefore they will be affected by the stresses that affect us all. This may be connected to many of the mental health problems that we see. On top of that, as Paris has just explained, they have often gone through a very intensive process of traumatising, which was done on purpose to destroy them. Those processes affect refugees not only as individuals but also as families. They affect their ability to link up with others and

develop supportive relationships. They also affect their construct of civil society and what living with others involves. These people have been through a process designed to destroy them.

All of the stresses we see you could probably say we see in an isolated form in the population here in Australia. But what we see in refugees is exposure to extreme, often multiple, trauma and extreme deprivation. The extreme deprivation could go from lack of access to food and education, to lack of access to health services and so on, and extreme loss, as Paris pointed out. But it does not end there. Then, what we have later, is that people move to another country, often through refugee experiences which are in themselves extremely traumatic and often involve further loss. But once they get here they confront a new society: a civil society where things work and where there are actually laws and people live according to constraints, which people coming from a situation where they have been repressed and persecuted for a long period of time would find quite strange—they would have no way to understand it. So we superimpose on all of those traumatic stresses the stress associated with adapting to a new environment and a very high and acute learning curve, having to learn the language and how to deal with a very different society. What we have is a very complex cocktail.

You mentioned how the services that these people need are different from those of the general population. In a sense, the services that we provide need to be specialised not only in working with trauma that has happened not as the result of an accident or the forces of nature but also in working with trauma that has happened directly as the result of people who set out to harm and destroy other people and communities in an ongoing way, often with the help of professionals. In many circumstances, doctors and psychologists have been employed to ensure that torture is effective as a tool to destroy people and to destroy and humiliate communities. That in itself is a field of expertise that is often quite taxing.

On top of that, the people that we work with come from a very large range of countries. We work now with more than 50 different language groups and very diverse cultures and world views. So it is important to ensure that the processes that we employ do make sense to them in order to be effective. That is another aspect that influences the services we can provide. Because trauma of the kind that we work with has affected people at various levels—as a family, as an individual or as a group—it is also important to ensure that the interventions that we put in place are also able to assist people at those different levels. So it is not only more effective but also more cost-effective and holistic.

Lastly, this is the kind of field that it is quite hard for the counsellors themselves and the people involved in providing these services to work in. Therefore, part of the specialty that our services have had to develop is ensuring that those services can be provided in a sustainable way. We have to ensure that our workers are not only trained to do the job but are also supported through it. So the way the agencies are organised needs to reflect that.

Dr Kaplan—I would like to add some comments about the psychological effects amongst children and adolescents. In the supplementary material we have provided demographic information which shows that 53 per cent of the humanitarian intake of refugees is under the age of 18. We have noticed a lot of psychological problems amongst those children and young people that are particularly captured by mental illness and, to a lesser extent, by psychological disorders such as post-traumatic stress disorder, anxiety and depression. The more common

manifestations of psychological problems amongst the younger age groups are through behavioural difficulties and family breakdowns.

We have teachers identifying children and young people who are withdrawn and unable to participate in school activities. Once they are referred to us and more comprehensive assessments are conducted then evidence of more severe problems can emerge. For example, in a recent case a young woman was referred to us after it was noticed that she was withdrawn. When we visited her to do an assessment it was revealed that she had actually witnessed her mother's face being blown off in a sniper attack in Bosnia and her father had been killed. Unbeknownst to the school she was in Australia without parents, in the care of a guardian uncle who really had no idea about her psychological difficulties. Formally, she would have met diagnoses for post-traumatic stress disorder and probably subclinical depression.

In terms of her emotional and behavioural life, she was severely debilitated and needed specialist assistance. The specialist assistance aided her to participate in the school setting. We also liaised with the school in order to facilitate their accommodating her needs. For example, she was due to do work experience and she was terrified of doing it. She had some scarring as a result of burns, which she was hiding. Alongside formal counselling, we facilitated an appropriate work experience placement that she could participate in without shame. A lot of our work is highlighting the debilitating and long-term effects of torture and trauma experiences which do not always necessarily show up as a psychological disorder in a diagnostic sense. However, the refugee population has a higher incidence of a post-traumatic stress disorder, anxiety and depression than the Australian population.

Mr Aristotle—The other thing to say is that we are obviously dealing with the extreme end of the trauma spectrum. We are talking about children who either were tortured themselves—the age groups of our clients who have been tortured range from as young as three years old through to elderly people—or witnessed family or friends being killed, tortured or raped. So the level of exposure to extreme forms of violence is extraordinary. The need for some specialisation is, in part, to deal with the sort of issues that Ida is talking about—to make sure that people do not fall through the gaps—and then, primarily, to help augment mainstream mental health systems so that through collaboration we can address broader issues over a longer period of time or work with mainstream systems that may be able to deal with acute incidences where someone may require hospitalisation and so forth. We primarily see ourselves as trying to relieve the burden on mainstream systems as far as possible by providing interventions that may prevent the need for people to seek that sort of support.

This certainly needs to happen in tandem. Australia is quite unique. We are one of the only countries in the world that has a national network of torture and trauma specialist agencies funded through the federal government. We have major concerns about the level of funding for it, but it is nevertheless a very positive thing that the Australian government has established this over the past 10 years. It does not happen anywhere else in the world. Some of the benefits were demonstrated, for example, when we had Operation Safe Haven with the Kosovars a little while ago. The national network was able to swing into gear very quickly and provide the resources to other services that were providing that care, develop a network of mental health services inside the safe havens and assist the government, at a state and federal level, to respond to that sort of need. Very few other countries in the world would have had the capacity to do that or the available resources developed through those agencies. So there are lots of benefits in seeing it as

specialisation augmenting the mainstream and being able to work in partnership with the mainstream.

CHAIR—I want to ask you about the contracts the agencies have with the Commonwealth. There are people discharged from detention on medical grounds, presumably psychological or psychiatric grounds, but what about those discharged for other reasons who might also have problems? What are the conditions and constraints on your work with the Commonwealth?

Mr Aristotle—Do you mean asylum seekers who have been detained?

CHAIR—Yes.

Mr Aristotle—Through the department of immigration there is a contract, which is just about to change over, called the Integrated Humanitarian Settlement Strategy. Up until September, the network of torture and trauma services is delivering the health access component of that tender. We facilitate initial health care, provide psychosocial assessments, organise physical health care and provide psychological interventions where required. It is the only component of the federal program that the government determined could be available to people being released from detention on TPVs.

CHAIR—These are people who do not have access to Medicare and who cannot work?

Mr Aristotle—Anyone released from detention on a TPV will automatically have access to Medicare, social security and so forth. They do not have access to family reunion and other settlement services relating to housing and English language tuition, but they do have work rights and access to Medicare and social security payments. There is a very substantial burden on asylum seekers in the community who do not have work rights and are ineligible for Medicare and social security payments and on the agencies assisting them, particularly where there are strong cases of prior traumatic experiences. I am not talking about all asylum seekers, because not all asylum seekers in the system have claims that are substantive. But significant numbers in the community who are being supported by agencies have very little access to health services and actually require them.

People are sometimes released from detention on bridging visas on health grounds. The availability of health care for them is variable. There has been greater recognition in more recent times of the need to provide more services. In fact, with some of the recent announcements we will probably see further improvements in that regard. But it has been very problematic in the past for people being released.

CHAIR—I would like to be clear about who is entitled to your services and who is not at the present time. Can anybody who has been in detention phone you up and say, 'I think I need your services'?

Mr Aristotle—Yes, they can. If they have been released on a TPV they can receive assistance through our federal funding from the department of immigration. It is short-term intervention. Beyond that, because most of us have state government funding, if someone rang up and said, 'I was released from detention a year ago and I'm not coping with the experience,' they would not be eligible for the Immigration funded program but our state funded services would pick that up.

CHAIR—Provided that they have been subjected to torture or trauma?

Mr Aristotle—Yes.

CHAIR—What if they have not? What if they have come here in other circumstances?

Mr Aristotle—We would identify where else they could be referred to for the receipt of treatment. We carry long wait lists at the moment, and it is hard enough coping with that.

CHAIR—How long does it take?

Mr Aristotle—It goes up and down, but wait lists in our respective services are about 12 months at the moment. It is a very long period time. They have extended beyond 12 months at different points. We have been able to pull it back down to six or eight months at different points, but really it hovers at 12 months or more, and that is a terrible thing.

CHAIR—How satisfactory is that?

Mr Aristotle—It is completely unsatisfactory that once someone who has been tortured and traumatised, particularly where it involves children and adolescents—or anyone, for that matter—has found the courage to say, ‘I need help for this,’ or ‘My children need help for this,’ they cannot get the assistance for up to 12 months. It can be quite soul-destroying for people.

CHAIR—You have also mentioned in your submission that placing individuals in isolation while they are in detention has a damaging effect. Would you like to talk about that a little and indicate what that means in terms of how much damage is done to people.

Mr Aristotle—There are issues around the provision of mental health services in immigration detention centres and whether or not agencies within the network of torture and trauma services believe they are adequate. Our view is that the quality and orientation of mental health services in detention centres has been very problematic and lacking. I would qualify that by saying that I do not think there has been a desire on the part of the government, officials or anyone else for mental health services to be lacking in immigration detention centres. In fact, their perception is that they have structured contracts and engaged providers who will deliver mental health services appropriately. So I would just qualify my comments by saying that the goal and desire has been to have mental health services of as good a quality as possible. But that has not been the outcome.

I think the outcome has been that, by and large, because of location, the nature of the contracts and the penalties associated with certain elements of running detention centres and so forth, the orientation of mental health care has been very problematic. The use of isolation centres in immigration detention has been identified because it has come up through the case work of services. They have picked up clients who have subsequently been released and who have talked a lot about the experience of struggling in detention centres. Sometimes as a result of reacting adversely to the environment, the way they were managed was to be placed in the isolation units of the detention centres. This was seen as a way of managing them. Those units are also used to hold people who had been deliberately disruptive or aggressive or had even committed an offence. So there was a mixed use of those facilities.

The experience of people being placed in there was that it further traumatised them rather than assisting them to deal with what was going on. It is in the submission because it came up through casework at times. People identified that experience in particular as being highly problematic. We are of a view that there are more dynamic and appropriate ways to deal with mental health issues inside detention centres, accepting full well that those environments are never going to be conducive to good mental health anyway.

CHAIR—You mentioned orientation. Is that code for a wrong attitude towards people with mental illness? What do you mean by that?

Mr Aristotle—What I mean is that I think there is too often a view that they can find a way of dealing with someone with a severe mental illness inside a detention environment when they cannot. That, I think, is in part due to a sense that if they admit or suggest that they cannot and the person should be released from the facility on mental health grounds then that is somehow interpreted as a failure.

CHAIR—By the management, not by the department of immigration?

Mr Aristotle—No. The act has always provided for the release of people if medical experts determine that their condition is such that they can no longer be cared for adequately in detention. They can be released on a bridging visa. That has been in the act since it was introduced several years ago. I have found it interesting to see that it is very rare that the mental health service providers orient themselves to make an assessment or a judgment about that issue.

So you often find that the only time people reach the point where they are released into a psychiatric hospital or onto a bridging visa is when it has reached such an extreme point and their mental health has deteriorated in such a dramatic way that there is absolutely no other option, whereas under the act both the previous Labor government that introduced the policy and the current government have always made provisions to prevent that occurring. It does not have to reach that stage before a bridging visa is issued or granted. In that instance, you are very dependent on the provision of mental health services inside the facilities to help identify that sort of thing and orient themselves towards looking for it. Personally, I believe that that has been lacking in orientation.

Senator HUMPHRIES—Could I just put my question on notice? I realise I am out of time. I just want to put my question on notice for you to take away and give us some information. On page 5 you mentioned:

We are also witnessing increasingly stringent eligibility criteria for welfare and social support services and the loss of a range of services with “open doors” or drop in facilities.

Could you give us a list of the sorts of services you are talking about so we understand what they are?

Mr Aristotle—Sure. We are happy to do that.

Senator HUMPHRIES—Thank you.

Senator MOORE—In terms of the process, I know that there have been significant waiting times in Queensland. That has been identified. Also, you allude very diplomatically in your submission to some issues in the services in Queensland generally. I know that the way you operate is that you work closely with the state services to provide the aspects. What kinds of things can be done to pick that up? What kinds of things can be done with the local agencies?

Also, the other issue that we have identified in Queensland is that most people are in Brisbane originally but they do not stay there, and then you have the issue that there are no services in regional centres. People have no right to move, because if they are going to have some access to treatment they are limited to living mainly in central Brisbane. It is as simple as that. Tell us about the kind of liaison that your organisation has with the state mental health providers and also the kinds of resources that are needed to pick up that great need—and I am talking very specifically now about Queensland, but it would be appropriate anywhere, I think.

Mr Aroche—I think in general there are resources needed for the specialist agencies in the sense that the role that we play is to provide specialist services. We develop new interventions that are able to work with the different groups that continue to arrive. Since we began working 15 years ago, the make-up of the refugee population has changed dramatically. With each new wave of refugees we need to find ways that work with them that are consonant with their world views. That is one area.

In general, there is basically a need for capacity building within the larger mental health sector, emphasising cultural sensitivity within services and emphasising training from the beginning. When you look at the training of psychiatrists, of psychologists and even of social workers, cross-cultural skills are not greatly emphasised, so that interface between the specialised services and the more generic services cannot work well. Often we make referrals that we then have to pick up again because the services that we refer to do not feel that they are capable of dealing with that situation, even when we have assessed that there may be a torture and trauma component that we are probably the best placed to address but that there may be a whole lot of other issues, sometimes dealing with more hard-core mental health issues such as psychotic disorders and so on. Often there are other kinds of problems.

Dr Kaplan—One of the best points of access, particularly in rural areas, is the primary health care system. The services have mainly focused on capacity building in respect of primary health care delivery, but there are a lot of barriers that one faces in respect of general practitioners and bulk-billing arrangements. Even though there may be access to interpreters, through the free telephone service for Medicare related services, you need a longer consultation in which to conduct those assessments or provide treatment. That is a commonly observed barrier to service provision. If primary health care were better resourced to address many of the psychological as well as physical effects amongst torture and trauma survivors, we could have shorter waiting lists. It is important to build that capacity. We have also noticed over the years that, where we do build the capacity of a service—such as a community health centre or even a school—to respond, they will refer the most difficult cases.

Given their nature, particularly where they involve family violence or other forms of family breakdown, our interventions need to be of a long-term nature. So that also fuels the long waiting list. I think one needs dual strategies: capacity building for other services, particularly primary health care ones, which are well placed to respond to many of the psychological needs

of survivors of torture and trauma; and increased capacity to actually respond to complex cases. We have had a case where a child has been kidnapped by the Taliban, the father has been killed and the mother has arrived with five children. Fortunately, the little boy had been returned but he had been tortured. The impact on that family has been huge, so the amount of work that one needs to do with that family to prevent long-term effects is considerable. Service providers know to refer those sorts of cases to us.

Senator MOORE—When they find them.

Mr Aristotle—Yes. To pick up that point, one of the difficulties of course is that, while we work in partnership with agencies as much as we can and collaborate with regional services where we can and provide training and capacity building, they tend to have waiting lists for demands on their own services as well. As a result of the training and the networking, many agencies have become better at dealing with the low- to medium-level cases in terms of complexity and trauma. As Ida said, we have actually helped people identify which are the really difficult cases. They are the ones we get, so these days we know every time cases make it onto one of our waiting lists that they are always going to be very difficult cases to deal with.

Senator MOORE—Yes, as they have gone through that process to get onto your list.

Mr Aristotle—That is right. It has been 10 years since any of the agencies have received funding through the federal health program, the PASTT. We desperately need additional resources to be made available through that program. It is a good program and I think it has been seen as being a good program, but it is a very small fish in the pool of a very big department and our ability to exert enough influence ahead of the demands around Medicare schedules and bigger issues is not so great. With a very modest increase, our ability to assist on all of those levels would be improved dramatically, including assisting the capacity of other agencies.

There is a trend at a state and federal government level to do a lot of case coordination, service brokerage and case management to get people into systems for support. I have reached the point of feeling dismayed that everybody is case managing, case coordinating and brokering services into systems that do not have the capacity—we are putting a lot of money into helping to get people into services but the services we are getting them into are saying, ‘How are we going to deal with this?’ There needs to be some balancing of that for both things to be fully effective.

I do not want to move off your question, Senator Allison, which we were speaking about earlier. I think that, with respect to the detention environment, the recent announcements, if implemented, will make a big difference. It seems that there is a very strong commitment to adjusting the ways in which some current practices occur, and there is now a serious look at mental health service provision—the Palmer inquiry will bring it out as well. I think all of these things are indicating that there have been real problems in the past. There is a crucial need for goodwill on all sides to be able to progress this stuff further to avoid, in the future, some of the difficulties we have had.

But to set something straight for the group, 90 to 95 per cent of our work in the torture and trauma services is with people that come in through Australia’s offshore humanitarian program. It is not with asylum seekers. The bulk of it is with people that successive Australian governments have chosen to resettle in Australia, and that is the primary focus of our work. We

receive clients who have been in detention because of other hats that I wear. But it is important to recognise that the primary area of our work is with that other group. It is an area where Australia, by and large, is amongst the best in the world in terms of how it deals with it.

Australian resettlement services, relative to other countries in the world, have to be seen as, if not the best, up there with the best couple. We have tremendous capacity to do this work really well, but the specific aspects of torture and trauma and the mental health component of that need additional support at this point in time. But I do not want anyone to have an impression that, as a group of agencies, we do not see the way in which Australia settles refugees, by and large, as anything but quite extraordinary.

Senator MOORE—Mr Aristotle, before you move off that point, would you restate the funding arrangement for PASTT. It is in your submission, but I think it probably would not hurt to have it restated.

Mr Aristotle—The PASTT was set up 10 years ago. Throughout that time, we have not received an increase in funding. We certainly received a lot of support from Senator Richardson, in the lead-up to the establishment of the program, Dr Lawrence, when she was the health minister, and then Dr Wooldridge, when he was the health minister. There were a lot of cuts happening around the different portfolios, and he was very proactive in protecting the PASTT bucket of money. That has been the case subsequently with other health ministers as well—Kay Patterson and so forth. So it is not that people have not recognised that it is important program; it is that they have never been able to get an injection of additional resource growth. Over 10 years the net impact is that we have gone backwards with increases in expenses, costs and salary levels and so forth. We see state governments as having a primary responsibility to provide funding for these things as well. Many of us work very hard with state governments to secure their contribution to this. But the federal PASTT enables our national network to do things that, as I said, no-one else in any other country in the world has been able to do. We are just struggling a bit under the weight of not having been able to get any additional support over the last 10 years.

Dr Kaplan—There is some recognition that the nature of the intake from a range of countries in Africa, which is 70 per cent, is quite different. I do not think there is a single person entering the country who has not been selected for their very high exposure to torture and trauma experiences. What is very different about this intake from, say, the intake from the former Yugoslavia, which was the largest intake for a number of years, was the lack of family integrity. There is a much higher proportion of single headed households—I think 25 per cent of the African intake is headed by women. They have large families with many children. Almost without exception, if you look at the background of those families, they have either been in refugee camps or in itinerant transit in places like Cairo or Nairobi, where they are very vigorously rejected. So they enter the country with higher needs than we have seen before. There is, of course, the layer of barriers to do with language and cultural differences.

Mr Aristotle—There are very complex family dynamics too. They are big families. There are eight, nine or 10 kids in the family. Take the South Sudanese, for example. They are not necessarily all here with their birth mother. There are all sorts of complexities that flow out from that that we need to respond to that are quite challenging, oftentimes. Then you get other cases. We have an Iraqi client, a father and his son. The father was detained under Saddam Hussein's regime with his son. The officials there believed that he had information about one of the UN

organisations that would be of use. He did not have any of this information. They tortured him for several hours in front of his son. They applied electric shock treatment to him, and he was beaten and humiliated in front of the child. He literally did not have the information to give but, not satisfied with that, they turned on his son and began to torture his son—he was about six years old at the time. Apart from the beatings, one of the things they did over a period of time was to gradually break the son's arm by creating a compound fracture of his arm that required surgery to heal.

On their release the father took the young boy to the hospital very quickly. Officials followed them to the hospital and stood over surgeons while they made sure that the repair was not done well. So this young child has very complex injuries that require ongoing medical treatment. He is getting it as a result of services and our health care system and so forth but you can imagine the complexities—the guilt that the father carries, though it is not his fault, as a result of what happened to the child; the level of anxiety that the child feels; what is like for them to take him back into a hospital. They know logically that it is to look after him here, but psychologically it generates triggers for him. These are the sorts of complex arrangements that we need to deal with, and if we deal with them broadly we are addressing mental health issues specifically as well.

CHAIR—We will have to end it there unless there is something really urgent that you need to tell us.

Mr Aroche—I would like to make a couple of points to put into context both the waiting list and the static nature of the funding. As this case shows, the services that people who have been tortured often require are stretched across their life span. As different things happen in their lives—they grow old; they lose their jobs; somebody dies in the family—they may need services later on. In the 10 years since PASTT was started we have had around 12,000 refugees coming into the country every year. That is an increase in the total population of 120,000. At the same time, I think the department of immigration has also got better at selecting refugees that are vulnerable and need to come into the refugee program. That has also resulted in an increase in the number of people coming into the country with severe problems associated with their torture and trauma experiences.

CHAIR—Thank you very much for that not altogether cheery news, but thank you for your submission and for appearing before us today.

Proceedings suspended from 12.43 pm to 1.34 pm

CLARKE, Mr Dave, Chief Executive Officer, Psychiatric Disability Services of Victoria (VICSERV) Inc

JACKSON, Mr Mark, Policy Officer, Psychiatric Disability Services of Victoria (VICSERV) Inc

WISSMANN, Ms Denise, Manager, Training Development and Delivery, Psychiatric Disability Services of Victoria (VICSERV) Inc

CHAIR—I welcome representatives from the Psychiatric Disability Services of Victoria Inc, which is known as VICSERV. You have lodged with the committee a submission, which we have numbered 347. Do you wish to make any amendments or additions to that submission at this stage?

Mr Clarke—No, although we have a prepared opening statement.

CHAIR—I will invite you to go ahead with that and, after you have finished, we will go to questions.

Mr Clarke—Thank you very much for having us here today. We would like to start by stating that we believe the state of mental health services and systems in this country is poor. The nation lacks adequate investment in mental health, and we do not believe there is any avoiding this issue. We support a number of the proposals provided to the Senate inquiry, including those which propose increasing national investment in mental health and increasing community based support and rehabilitation. Our submission addresses in more detail where, in our opinion, new investment needs to be made, how this can be done and the benefits of that investment.

VICSERV is the peak body for community based rehab and support services in Victoria, where, compared to other states, community based programs are significantly more highly developed. Yet, even in Victoria, the situation is bleak. As we know, a number of factors are creating a long-term squeeze on the mental health dollar—and on the health dollar generally. There are a number of areas in health under pressure. This pressure will continue to increase in the coming five to 20 years. As a nation, we need to revisit the assumptions made about the proportion of our GDP that we invest in the health of our citizens, including their mental health.

In addition to this, regardless of any new funds coming into mental health, there is a great need for better and smarter approaches to delivering a comprehensive mental health system and improved outcomes for consumers. We need a system which does better on reducing pressure on acute care and emergency wards. We need a system which does better in preventing relapse. We need a system that promotes higher rates of recovery for people with mental illness, so that a greater proportion of people who become ill do successfully recover. We need a system which acknowledges the need for hope and for opportunity for people who experience mental illness—and the impact of these on their recovery. This can be achieved, including relapse prevention, by investment in and the introduction of a wider range of community based support and rehabilitation services.

People often talk about the pointy end of mental health being emergency wards. It is not. The pointy end of the work that is done is to prevent people ending up there in the first place. This work is done in community based programs or not at all. Evidence for this exists through research done over many decades. The third national mental health plan refers to increased community and recovery focus, but this is yet to filter down strongly enough to the states. Far too little is being done too slowly. There is still an excessive focus on clinical interventions and a lack of focus on psychosocial rehabilitation and support, and a combination is needed. There is a lack of expertise in bureaucracies about community based rehabilitation and support and a lack of knowledge of psychosocial rehabilitation, resulting in sustained clinical focus. Most advisers and opinion leaders are from clinical backgrounds and lack this wider perspective, and so we remain stuck in an outmoded delivery system, post deinstitutionalisation, which, despite the evidence, continues to increase its focus on clinical interventions and provide knee-jerk reactions to crises, by increasing hospital beds instead of funding services that would prevent people from ending up there in the first place.

Services which need to be widely expanded include home based outreach models, housing support programs and mutual support self-help programs that allow people to work to help themselves and help other people in the same situations as themselves, including people with psychiatric disabilities and their families. These sorts of programs foster and support increased access to employment and to the community and generate opportunities and hope for people so that they can actually live a life of recovery. They produce outcomes which ultimately contribute so powerfully to the process of recovery. There is already the intellectual property and capacity for growth in these areas, as well as a potential policy framework. Just one element of this is that VICSERV, for example, has a comprehensive training and professional development program and practice guides for workers which are the only ones in the nation. We have a national journal and an extensive library, and the Victorian PDRS sector provides the only comprehensive model of philosophical and practice integrity to help reconfigure the national mental health system to one which is more balanced.

Finally, community based rehabilitation and support is not about attendant care or babysitting people in the community. It requires skilled work undertaken by skilled and experienced staff. To achieve this, programs need to be properly funded. In Victoria, there has been in the past an excellent system of rehabilitation and support services. That was built up over the past 15 years and it is now being bled dry by the government in an attempt to reduce the skill requirements and expectations of services. At this rate, Victoria will not provide good examples of effective services for much longer, unless there is a recalibration. Before any questions are asked, I invite Denise to provide a perspective which helps to distinguish the nature of our services from clinical services and provide a bit of an insight into the impact that they can have on people's lives.

Ms Wissmann—Having been a support worker in these services for over 20 years, the thing that I have witnessed that psychiatric disability rehabilitation and support services provide people with that is an adjunct to the clinical service is support in the sense that when somebody experiences a mental illness it is hard enough to come to terms with having the mental illness, let alone the diagnosis, the associated grief, the huge disadvantage, the disenfranchisement of their potential and all the stigma. What people seem to need is time and space to recover and come to terms with the fact that they now have a mental illness and their life is going to be totally different to what they thought it was going to be. When they are given a diagnosis they have the

choice of either accepting the diagnosis or rejecting it. Sometimes people need the middle ground, and we provide that middle ground—a space in which to come to terms with it and deal with it.

We help people to learn to accept their mental illness, to learn to live with it, to learn the skills to cope with it and to gain a picture of themselves as valid and valued outside of their diagnosis. We do this through: the development of a crucial therapeutic relationship, which workers develop with clients; the provision of a safe place to be—in terms of our day programs and residential programs; peer support, where people can be with other consumers who have also gone through the same process; personal development programs; and skills development. Our services provide those things currently, and we are the only services in Australia that provide them. Those things are not provided outside of a community based setting as far as I am aware. They are absolutely crucial in terms of a person's recovery.

CHAIR—Mr Jackson, do you have anything to add?

Mr Jackson—I was not going to add anything.

CHAIR—Mr Clarke, could you make it clear where your funding comes from at the present time?

Mr Clarke—VICSERV and what we call the PDRS sector—psychiatric disability rehabilitation and support—funding comes from the state department of health through its mental health branch.

CHAIR—On what basis are you funded?

Mr Clarke—Are you talking about the PDRS sector or VICSERV itself?

CHAIR—Whatever you need to tell us.

Mr Clarke—We are funded within a policy framework to provide rehabilitation and support to people with high levels of psychiatric disability and severe and enduring levels of psychiatric disability in the community. It is not illness based; it is disability based, in that access to services is designed around the assessment that a person has of significant disability. So, while most of the clients we work with have what we call low prevalence disorders, such as schizophrenia and bipolar disorder, there is a proportion of clients who use services and may suffer from severe depression and an associated high level of disability as a result of that depression.

Services are funded in five service types: residential rehabilitation, home based outreach, day programs, planned respite care and mutual support self-help. Each has different models of service, but they are all designed to work with people within a recovery framework, working from the basis of a psychosocial rehabilitation framework to assist people in their lives in the communities they are actually functioning within.

CHAIR—And you do that for the whole of Victoria?

Mr Clarke—We do. There are more than 190 programs around the state of Victoria and the state invests around \$55 million per annum in those programs.

CHAIR—Is that \$55 million a figure based on the number of people in Victoria or the number of people that you see? Is there a cap on it? How is the number of people you see determined—and what level of staff you have, for instance?

Mr Clarke—It has simply evolved. In our view, it does not relate to the demand. Demand is significantly higher. In fact, within four of the service types, excluding mutual support and self-help, our services are contracted to work with around 9,000 clients. They work with 12,000 clients because they come from a community base and have a historic tendency, which governments love, to work with more clients than they are actually contracted to work with. They have more than 3,000 clients on waiting lists. So there is certainly a significant amount of unmet demand. That is in a situation where only just over half of our services even keep waiting lists. We can assume that the demand is even higher than that.

CHAIR—In settling on 9,000 clients for which you are funded, what considerations have been made—or is this just an historical figure?

Mr Clarke—Under the CSDA—and this is why Victoria is different to other states—a couple of people that I would call policy entrepreneurs within the state Department of Human Services at the time created this service type for the first time and linked CSDA funds, which also included growth funds, to this particular type of service. Since that time there has continued to be growth in the area, which was facilitated by successive governments since that time. The Liberal government in the mid-nineties came up with the carer initiative that put \$6 million of new funds in. But the growth has not been evidence driven or data driven; it has been politically driven. There was an underlying commitment through the nineties to increasing the amount of support in the community. The initial funding showed that these programs were working and successful, and they did receive a fair bit of kudos for the work they were doing.

There is still a significant lack of effective research to be able to properly quantify, in this new evidence based world that we live in, the benefits of services. For example, it is our assertion that our services generate more than the total value of their funding in relapse prevention value alone. However, we cannot prove that at this point in time, because it is extremely difficult to access the funds to conduct the research. That is a particularly important area that needs to be addressed.

CHAIR—That would be something you would recommend to the committee?

Mr Clarke—Most certainly.

Mr Jackson—It was in the recommendations in the submission.

Mr Clarke—I think the Third National Mental Health Plan does refer to recovery focused services. It also refers to the need for a new and significant focus on evidence. In many ways it implies that, if something does not have evidence, it should not necessarily be funded. That is fine, but one of the problems we have in mental health is that we have still a significantly medically-driven model, which is more comfortable with and has historical funding flows for

research and evaluation. Where we need the growth is in the community development side of this work—that is, working with people in their lives in the community from more of a social model of health, which is more the basis of the services we are describing. We do not have the historical focus on the building of strong evidence for that. In some ways I think we are being punished for that now.

Senator HUMPHRIES—You made a comment before, Mr Clarke, about the Victorian government bleeding something dry. Can you just repeat that comment?

Mr Clarke—For the past five years we have been engaged in discussions and continued advocacy with the state government of Victoria because, whilst there has been significant growth in Victoria, the basis of the funding of services has not been adequate and, as a result, the growth has to some degree masked the viability problems that the sector has had. Services have continued to grow and have used growth funds to keep their heads above water, but the funding levels for services are not sustainable. There has been a pricing review of PDRS services in the past 18 months and new funds have come into the sector, but unfortunately the bureaucracy made decisions to apply those funds to increased accountability measures and increased outputs and they have reduced other small areas of funding such as minor capital grants and assistance in replacing the motor vehicles which are so important to home based outreach programs. With the reduction in those funding areas, virtually all of the new funds that were supposed to go into the viability and sustainability of services have been absorbed into increased requirements for services to stand on their own.

So we still have a fundamental problem in Victoria where the funds that are being provided are not being provided at sustainable levels. Whether we talk about it in the context of EFT, price per client, or price per hour of service delivery—there are a lot of different ways to describe it—we can say that at the moment we do not have sustainable funding levels. For example, in our largest and most flexible area of service delivery, home based outreach and intensive home based outreach work, which is working with clients in their particular environments—whether they are homeless, living with parents, or living in public housing—we do not have adequate funds to keep enough workers on the ground to do the levels of work that the government is expecting. It is my personal opinion that PDRS services and the community based programs are seen as cheaper options for service delivery and, as a result, there is a willingness to let the quality of those services suffer to some degree. This is something that we really need to challenge nationally.

As we have said in the opening statement in our paper, this work is complex work and effective psychosocial rehabilitation requires highly skilled workers who do effective work with clients. They need training and professional development, and they need to work within a service that can afford to buy the skilled staff to work with people. We are simply not funding these services adequately to do that. There is a willingness to fund the community based programs at significantly lower levels than clinical programs, although the requirement to employ skilled workers is almost as high. So it is a complex problem and it leads to situations where our services increasingly need to employ young social work graduates, who may never have worked with people, to work with probably the most complex group of clients. Those clients have comorbidity in a range of areas and a range of social and community problems laid into the mental illness they might have, as well as associated disabilities.

Senator HUMPHRIES—Because a graduate is cheaper to employ?

Mr Clarke—That is exactly right. They do that rather than employ skilled people who have worked in the social community services system for some years and can bring a level of maturity and insight to that work. That is one of the big problems. We can employ people from a range of disciplines and train them in psychosocial rehabilitation. So we do not necessarily have a work force demand problem. Unlike the rest of the mental health system; our problem is being able to afford to employ staff who are highly skilled enough to get the job done.

Senator HUMPHRIES—How has VICSERV's case load changed in the last five years?

Mr Clarke—Are you referring to the sector, VICSERV being the peak body?

Senator HUMPHRIES—Okay.

Mr Clarke—As an opening gambit I can say that in relation to the sector's case load—and my colleagues might want to comment on this—there is no doubt that the clients that have been presenting to our services over the last decade have become increasingly more complex. There are, more commonly, high levels of critical and urgent need, which have caused our services to run managed waiting lists. Even though they are working above their client numbers, they see clients on the waiting list who have critical need and require interventions that would not necessarily be normally provided by our services. There are issues about being able to provide adequate support to those people to try to keep them out of hospital. So we have gone into methods of that nature. But my basic statement is that clients are more complex. There are high levels of dual diagnosis and there are drug and alcohol problems that also need addressing.

Mr Jackson—On the viability of the sector, we do not have the funds to maintain our level of sustainability, and that is totally ignoring the increased demand that has been put on the sector.

Senator HUMPHRIES—I assume that the clients that your organisations deal with tend to be lifelong clients.

Ms Wissmann—That was a traditional view. In the early days we were working with people who had spent most of their lives in hospital—they had been in hospital for 30 or 40 years. The idea was that we were probably going to support those people for the rest of their lives, but now, with the concept of recovery and the process of rehabilitation, we see our work with people as being shorter term. The time span for each individual varies enormously. So, no, we do not see ourselves with long-term clients.

Senator HUMPHRIES—What is the average period of service of an average client?

Mr Clarke—In home based outreach, client turnover in Victoria is between 26 and 28 per cent at the moment. The average stay in home based outreach programs is around four years, and it is very close to that with day programs. Residential rehabilitation services are more intensive services that involve a group of clients, for example, being in one place. That might be a block of flats or a house with six beds in it. That might have 40-hour service from workers. A more intensive service might have 24-hour, seven-day support from workers. The turnover there is 50 per cent, so the average stay is two years in those services—and so it should be, it is a more

intensive service and in many ways it is a step down type of model. That reflects the fact that clients are now younger and less well and there are increasingly fewer clients that come from the institutionalised environment that Denise is referring to.

We expect recovery; we expect people to ultimately become independent of our services. That is the goal. I think at the moment those sorts of turnover rates are reasonable. If you have effective clinical support and treatment and effective psychosocial support and treatment, you should be expecting clients to recover. Not all clients will, and some will take significantly longer than others, but you are working on a throughput model rather than necessarily a maintenance model that we could have expected immediately post institutionalisation.

Mr Jackson—We are not an alternative to clinical services; we work hand in hand with clinical services. The former clinical treatment, which was in large institutions and with drugs that did not work very well, created a spectrum of people who became quite disabled, hence the current spectrum of need that we service. There is a reducing population of highly disabled people in that long-term institutionalised area and, as our service framework has evolved over the last 50 years, post war, we have developed strategies and insight as a society about the ability of people to recover from mental illness, so our practice frameworks have also developed to expect people to recover. Practice, or clinical service, has evolved as well—from using drugs that have severely disabled people to using drugs that are working quite well. So the psychosocial framework can also change to work better with those newer drugs.

Senator HUMPHRIES—If you were not there, what would happen to these people? Would they be more likely to end up back in clinical settings?

Mr Clarke—Definitely. As I stated earlier, our focus is on supporting people to develop hope and opportunity in their lives, and our services do that. People move on, and they may experience illness for their whole lives, but ultimately they develop the skills and the strategies to cope, access the work force, recalibrate their lives, re-engage with social groups and all that kind of stuff. Mental illness is a roller-coaster ride for people, whether they like it or not. When the roller-coaster is down, more intensive support is required, and our services prevent hospitalisation and presentations in emergency wards. That is what these community based programs also do.

Mr Jackson—They also prevent homelessness, because many of those people go straight into homelessness and become a great social cost in many different ways.

Senator HUMPHRIES—Is your service mainly delivered through paid staff or volunteers or is it fifty-fifty? How is it broken up?

Mr Clarke—It is mainly delivered through paid staff. The exceptions to that would be in the mutual support self-help service model and the planned respite care service model, where there are a higher proportion of volunteers. For example, with some planned respite care programs there might be a volunteer coordinator who coordinates people who conduct short-term respite activities with clients. In mutual support self-help programs there are organisations such as GROW which are designed around a coordinator who coordinates a series of self-help groups where people who have been through the self-help group coordinate the next self-help group and work with other people from their own personal experience of mental illness. Certainly they are

important, but it is also equally important to understand that this is not a voluntary sector. The interventions, as we said earlier, need to be skilled. The training—Denise has written Australia's only curriculum on psychosocial rehabilitation—is really set at postgraduate level and it requires people with not only the capacity to do that training but also probably a bit of life experience as well.

Ms Wissmann—The qualification groupings of our staff are: a fairly high percentage of social workers, psychologists, a lot of ex psych nurses who have moved over into the community-based sector, occupational therapists, teachers and—

Mr Clarke—Community development workers—

Ms Wissmann—people such as those who, for example, might have been plumbers or whatever and have decided to have a life change as adults. Those key groupings are the main groups of our employed staff.

Senator HUMPHRIES—You do not give us a list of the organisations that make up VICSERV—could you do that?

Mr Clarke—Yes, we can.

CHAIR—And they are spread right around Victoria?

Ms Wissmann—Yes.

CHAIR—And regional centres as well?

Mr Clarke—Yes.

Ms Wissmann—The framework of Victorian mental health services is that every region has one of each service type at least. But in some of the rural regions they have a lot of area to cover, with, say, a one-day program or a home based outreach service.

Mr Clarke—It is probably worth mentioning that it is not so much about form as it is about function. By that I mean that our services are run by different types of organisations. We have six or seven community health centres in Victoria delivering PDRS services. We have a significant number of stand-alone PDRS organisations—they are incorporated bodies; that is all they do. We have multi-program organisations, which may or may not be church based. These include: Mallee Family Care; St Luke's Anglicare; Aspire in Warrnambool, which is a stand-alone multi-program organisation; Pathways in Geelong; NEAMI in the north-west; Western Region Health Centre; Eastern Access Community Health; Mental Illness Fellowship, which is a large state-wide organisation; and Richmond Fellowship of Victoria, which is a large stand-alone, state-wide organisation.

The key to these services is that they are delivered from a community based framework. That is very, very important. It is an entirely different structure and cultural framework for service delivery than area mental health and, again, it needs to be. Whilst saying that, I will underline Mark's comment that we have to work effectively with clinical services. There are two very

significant elements of a person's life in the way that their illness and associated disabilities are treated: that they get their clinical needs met and that they get their psychosocial needs met. The focus at the moment is far too much on clinical needs still. It does not matter if it is a community health centre, a stand-alone PDRS organisation or a church based organisation running it, as long as the service framework is clear and as long as it is delivered from that social model basis and that community basis.

Senator FORSHAW—Just picking up on that and on the discussion that you have been having, and noting the comment in your submission that there should be—in your words—‘a national network of well funded, well trained, professional and respected community based rehabilitation and support services’, it is very often put forward that we need a national approach to a particular issue. I think people see that as a worthwhile objective in this area of mental health. The difficulty is: how do you actually establish that national approach or, in this case, a national network?

I assume you would suggest that the sort of model you have here in Victoria could be utilised nationally, but do you have any specific ideas or proposals about how we would actually get a national network implemented? Jeff Kennett said this morning that you would need the premiers and the PM to use the COAG process to drive a lot of the agenda and if you get that political will that is one side of it. But, structurally, you have state governments, private sector and non-government agencies involved. Can it be done easily, and what sorts of practical things could we put forward to say, ‘This is how it should be done and this is who should manage it or fund it’?

Mr Clarke—It can certainly be done. If we look at the history, when the National Mental Health Strategy was first produced it provided a significant amount of drive and influenced the states very significantly. I think the degree to which it influences the states today is not so great. In many ways it has almost run its race, because it is just seen as words on paper now. The other thing that has caused a dynamic in recent years is having state Labor governments and a federal Liberal government. I do not see strong leadership from the federal government in mental health, but I can understand that there are a number of dynamics that might have created that.

It certainly does need a national approach and I think that there is a framework there for national policy, but it does have to be done collaboratively with the states. We are seeing New South Wales now funding community based programs, because some of our organisations are going up there to deliver services—and to Tasmania and to South Australia, where our service providers are now exporting their services and setting up services in those states. Queensland is ready to do that as well.

I think that there is a need for a national policy initiative which is developed with the states and which is based on the acknowledgment of a need for greater investment in community support programs, and there are component parts to that. There are specific components which would make it successful, and you can look at the Victorian experience to draw some wisdom and knowledge from that. I would not necessarily say you should copy the Victorian experience but you can certainly draw wisdom and knowledge from the development in Victoria as it is taking place. The other state peak bodies, such as the Mental Health Coordinating Council in New South Wales and its counterpart in South Australia, are developing. They need to be supported to develop, as VICSERV has been able to develop, and to provide a home for

intellectual property, practice development and systemic development where you have a body which supports the NGOs to be more effective and to really build their quality—

Senator FORSHAW—Sorry to interrupt. It sounds like you are saying the structures are there in the states and it is a national policy and combined funding initiative, rather than some sort of overarching structure, that we need to pull this together. Am I right? Is that what you are saying?

Mr Clarke—There are different ways to do it but, yes, I think you could work with the current structure if the states and the federal government were willing to sit down and discuss this issue properly and work through how it could be achieved. I know there are a number of political factors which would impact that, but I do think this is a really important national issue and we are not going to get anywhere if the states or the federal government use this issue to beat each other over the head with. We really do need to try to develop a national approach. As to whether or not you set up a separate body to do that, I would not have a comment on that. Other people might have a stronger view about that, but I do think that this does need to be driven nationally.

Even the Victorian government with its diminishing attitude towards community based programs has to revisit its own attitude about this stuff. Here we are, sitting here talking about how well developed Victoria is, but things are not too rosy here right now—in the best state of all when it comes to community based programs. So I think that the Victorian government needs a kick along on this issue as well.

Senator MOORE—We do not have anything of this status in Queensland. It is slowly evolving but we have not got to your level yet.

Mr Jackson—There are some interesting models in Queensland though, for service delivery.

Senator MOORE—They are evolving, but they are not too good in the north.

Mr Clarke—Queensland's Project 300 was a very significant project, but what it involved was brokerage and at the end of it all, after significant expenditure, there was no body of knowledge and skill and capacity to take the next step and deal with the next 3,000 clients. It was all just brokered away. That is what we have had here in Victoria—the capacity to build a practice framework and build organisational and programmatic capacity and be able, under great financial pressure, to seek to retain staff and skill them up to do the work.

Senator MOORE—I have two questions. Firstly, how do you talk to other states? What you operate is working in Victoria but you obviously have national knowledge and people are feeding in and sharing and saying, 'Look, we do better.' Secondly, this morning we have heard significant evidence about the role of the consumer and the lack of consumer voice in a lot of the plans that are going on—

Mr Clarke—You will hear more about that this afternoon too.

Senator MOORE—I am sure we will. In your recommendations there is a theme through many of them about getting consumers involved, and their role. I would like to hear more from

your group about what you see as the role of the consumer and how you operate in your organisation.

Mr Clarke—They are really tough questions to answer because there is a lot of debate between us and the statewide consumer peak, VMIAC. Representatives from VMIAC will be addressing you in the next little while. My ears are burning a little bit because Isabell Collins is sitting behind me—

Mr Jackson—To address your latter question, there are a couple of levels of how consumers are involved or can be involved. The most fundamental level is at the point of service delivery—how they actually interact in charting their own journey of recovery. There is a sense of empowerment and whether that be with clinical services that is more for other people to comment on. Fundamentally, with our services it is a central part of service delivery. The consumer needs to design, in conjunction with their key worker, how they are going to begin to rebuild their relationship with themselves, their relationship with other consumers and, most fundamentally—and this is an area that we really need to develop—their relationship with the broader community again. And drifting slightly off topic here, we need to undertake a community development process. How does a community start to accept people back into it when there is so much stigma attached to the problem?

So there is that consumer level right at the very coalface. Then there is the more structural level of how consumers help to design services more generally. That might be through consumer advocates within organisations or within individual PDRS services. Or it might be through more peak body interaction or a political or governmental advocacy role.

Mr Clarke—The individual situation for consumers is service. We have the bell curve of effectiveness in all areas including consumer engagement. But the aspiration of PDRS services is that it is the client's recovery—it is their program and it is their life. The job of the worker is really to be there and stand by them and say, 'How can I help in your recovery? Let us work something out together and let us work together.' Firstly, it is about empowerment at the individual level.

Then there is the organisational design and delivery. Different organisations involve consumers at different levels, including having consumers chair or run their boards. I am aware that some areas of the consumer movement are arguing very strongly for entirely consumer-run services. That is another way around the design of things. I certainly would not create an argument against that. They would become a member of VICSERV ideally and would contribute to the way we develop policy and supportive services. Our focus is on promoting and supporting the notion that services at the individual level ensure that consumers are empowered, not disempowered, by their relationship with the service. That is a challenge.

At the third level you have organisations like VMIAC here in Victoria. VMIAC have made it clear that they are short on resources. Compared to other states they are doing pretty well, but that does not mean that they are doing okay. The mental health system needs to value in meaningful ways—like with funding—the voice of consumers, so they can properly influence the development of services and systems. Even though there is a cost, it is the classic problem of governments funding advocacy organisations to advocate against them. But, personally, I think that is a very healthy thing. I think the consumers' voice has to be funded effectively.

Mr Jackson—Sometimes in our sector in Victoria we have quite an amount of independence from the area mental health services. In other states that is not the case; they are funded from the mental health service. How are you going to advocate against clinical services in that case? How are you going to build a consumer voice? Your first question was about—

Senator MOORE—My first question was about how you get the knowledge and the networks, seeing that you are peculiar—in the nicest sense of the word: that is, there are no sister bodies in other states.

Mr Jackson—There are sister bodies in other states, but in the last few years we have really started to set ourselves as leaders in Australia. One way for us to express that is through our journal, *New Paradigm*.

Senator MOORE—Which you said was national?

Mr Jackson—Yes, it is now national. Also we are marketing our state wide conference as more of a national or international conference. Is that right?

Mr Clarke—That is right. Every two years we run a national rehabilitation conference that also has a significant New Zealand contingent. This year we are also running it in partnership with Richmond Fellowship Asia Pacific. So we will have 800 or 900 people at the conference. The other thing is that the board at VICSERV has seen strategically that the Victorian mental health system could be improved by a better national system of community-based rehabilitation and support. As result, I have taken a lot of time and energy to visit my compatriot peak bodies in other states—the NGO peaks, as they call them. We do not use the term much in Victoria because it is not about form but function. We are actually rehabilitation and support, but in other states there is a lot of the classic ‘poor cousin NGOs’ attitude. It is worse than in Victoria. I visited them to offer resources, advice and the opportunity to get involved in the delivery of our practice guides and our training and professional development programs. My job is to do that at cost; I am not even trying to make a profit out of it. Even the small amount of resources that are required are a real stretch for those peak bodies. Plus I think they also have their own issues—they are wondering about where they are going. Organisations like the Mental Health Coordinating Council in New South Wales are slightly different and do have a broader church of representation. So it is a little less clear for them at this time what their direction is.

Mr Jackson—And the Queensland peak body has just swapped over in the last year, hasn’t it?

Mr Clarke—There is a lot of that movement going on. But in a recent forum in South Australia I urged the state government to support the newly emerging peak body there and make it strong, because if you can make those peak bodies strong you can allow them to contain the intellectual property and knowledge that VICSERV has been able to develop.

Senator SCULLION—In terms of recruitment, I guess it is self-evident that the process to provide more community based rehabilitation and treatment has moved away from a clinical type vocational role. I would have thought it would have produced a need for a different demographic in the workplace. How difficult has it been to fill those roles? You touched on the fact that Denise had been involved in curriculum development. In fact, the sorts of people that you were looking for in that particular range were postgraduates with life experience. How

difficult has it been? Have you had heaps of people lining up to fill those roles? Can you give us a bit of an indication of how hard it is to recruit people into those roles?

Ms Wissmann—I think it is a little bit mixed.

Mr Jackson—It depends where you are too.

Ms Wissmann—Yes. I think it is harder in the rural and regional areas. Sometimes they do not have enough people applying for the job to even have an interview process. I think there is variability in terms of pay rates. It is always more interesting to work in a clinical service if you are going to get paid a lot better. That is why we tend to attract new graduates, people who are still studying, people who are having a life change experience or people who actually want to do the work, because they are more committed to it. The passion for the work is what actually draws people in and keeps them there. So it is difficult.

Senator SCULLION—It seems that a principal plank of the policy in terms of personnel and how you manage many of these people at the community level is that you need a principal key worker or a manager as part of your ethic. I think that seems to be a fairly laudable principle. But there are potential difficulties in recruiting, particularly in regional Australia, as you said, in order to hinge this process and policy. Whilst it would be very good, it just seems that there may be a real weakness in that approach, in that the approach simply is not possible in that framework—it is just not possible in areas where that recruitment demographic is not there.

Ms Wissmann—I guess one thing we have done to help make the work more valid, inspiring and interesting is develop a knowledge base for the profession of psychosocial rehabilitation practitioner. This has been a journey. When I started work we had no idea what we were doing—we were just doing it. In all of the years that I have been reading, studying and working on it, we have come to a place now where we know what we are doing. Now people can be trained in it and they feel they have a real job—they are not just running a day program or an art class. They are doing something that actually has much more meaning than that. I think that is the drawcard of the work. David was talking about trying to help the other states to develop this professional identity as well.

Mr Jackson—I came from an academic background into doing mental health work—through being a musician—so I have a patchy background. Now I am back in the research field. For me and for much of the sector it is so much about relationships and making a connection with people who are extraordinarily disconnected. That is what is missing in our mental health system. Certainly, you can provide the drugs to help people recover from the symptoms, but the disability that comes out of having a mental illness is primarily about disconnection. We seek to train people to value the practice of building relationships, building trust and—this is the most fundamental thing of all—rebuilding hope for those people. That is the quality we really seek in our employees.

Ms Wissmann—That is why a plumber can do the work if they have the heart, with our training.

Mr Clarke—Yes, you have to have the training. Really what we are saying in response is that the recruitment demographic in this area of mental health service delivery is probably there more

than it is in any other area of mental health service delivery. It is probably something that is a very positive thing, given the pressures that will be being reported to you about work force demand and inability to meet that demand.

Mr Jackson—There is much more scope within the sort of work we do, the focus of the work we do, in recruitment. And I am from a regional area as well.

CHAIR—Would you be willing to give the committee some of your training materials so we can see the kinds of things you teach and the way you work?

Ms Wissmann—Yes.

CHAIR—We are glad you talked about the plumber because this morning we talked about hairdressers. In Horsham, hairdressers have been given training to assist people. Thank you so much for appearing today and for your submission. It has been really useful. We have gone well over time as always. I apologise to our later witnesses.

[2.26 pm]

HOCKING, Ms Barbara, Executive Director, SANE Australia

CHAIR—Welcome. The committee has your submission, which we have numbered 133. Are there any additions or alterations you want to make to that document at this stage?

Ms Hocking—I have no alterations, but I have brought copies of our recent help line report, which presents a summary analysis of the over 16,000 telephone calls our help line took in 2004.

CHAIR—Is it the wish of the committee that the report be accepted as evidence? There being no objection, it is so ordered. I now invite you to make a brief opening statement, after which we will go to questions.

Ms Hocking—It was very interesting listening to the previous witnesses because there is a lot of commonality in the sorts of things we are saying. First of all, I wish to reiterate what David Clarke said about increased funding to the sector being an inescapable fact. We cannot do anything more without more funding. I think that is really important to say straight up. The other really critical thing is to have major action to reduce stigma at all levels. Without that, the other things are just like poetry. I am talking about stigma at every single level. I am not just talking about the man and woman in the street; I am talking about the man and woman in the highest office of the land, because that is where the priorities are set. I think it is really important to educate right across the board in terms of what mental illnesses are, what the impacts are on people's lives and the importance of providing decent services and supports for them. I think a major national destigmatisation campaign is really important so that not only we get the priorities established but also we get the man and woman on the street demanding that action follows from that priority setting. It is at all levels, and I have to say that includes within health services as well. We get a lot of reports about stigmatising attitudes within health services.

Following on from that, I am conscious of the things that were not talked about earlier. One of the other major important things that comes through in terms of the demand for our help line is to have improved and increased access to psychological support. That is something we hear again and again. People are asking for those services. The evidence is increasing about the effectiveness of psychological treatments. It is so important to have them as Medicare funded items. I do not think there is any way around that either. We commonly hear from people that the only things clinicians do is write prescriptions. At the moment, the only thing that clinicians can do that is Medicare funded is write prescriptions. So it is not just that that is the only thing people feel is effective; it is the only thing that can be done effectively at no cost or low cost to the patient in that setting. I think that is incredibly important.

We heard expressed very articulately and clearly the importance of the community support sector. I can only reiterate that. I think that we are only giving part of the treatment if we look only at the clinical setting. We have got to provide the other services and supports that help people maintain optimal health. The word 'recovery' is used very loosely across the board. It does not always mean that people regain their original level of functioning; it means that they have reached a level of stability where they feel that they are a bit more in control of their lives.

Without those really important services, that does not happen. You are really just looking at a revolving door.

One thing that was not mentioned there is the importance of family education and support. If these things are all in place, there is going to be less need for acute beds. What I would hate to see come out of this is a knee-jerk reaction of opening more beds, because that is not necessarily going to be in the best interests of people living with mental illness. I think if we have good community supports in place—supported accommodation, recovery based rehab programs, family education and support—there is going to be less need for those acute beds, particularly if we have improved access to what I call true asylum or sanctuary: places where people can go when they feel they may be becoming ill, before they have an acute episode. In Victoria they are called step-up/step-down programs; you may have heard those mentioned before. There really does need to be more of those sorts of things. So there is a whole suite of services and supports that should be available.

Once we know what is needed, we have to get over the great federal-state divide, which was alluded to a little bit earlier. I do not have a simple answer to that, I am afraid. Your heads are going to be much better at that than mine would be. We just know it needs to be done. It is not working at the moment. The man and the woman on the street want a seamless service. They do not need to know who is funding it or who is planning it; they just want the programs that they need. There needs to be much better communication and cooperation at those levels. Within state services there needs to be much better cooperation between, say, mental health services and alcohol and drug services—those sorts of things. You need more joined-up thinking both within the state and between the state and federal departments.

Another point is that consumers and carer involvement needs to be integral and meaningful, not tokenistic as it very often is. You will also hear about work force issues again and again. In your discussion with the VICSERV folk you were talking about the need for skilled, compassionate staff. There have to be real incentives to recruit them to and retain them in the system. There is also a stigma operating in terms of getting people who want to work in the system and want to stay there.

Finally, you have to have some sort of independent body that is going to monitor how all this happens, someone keeping check that what you set out to do is in fact happening, and reporting on that promptly. We do get mental health reports at the moment, but they tend to be three or four years out of date when we get them, which is not that helpful. It is better than nothing but it is not that helpful.

CHAIR—Can I pick you up on that last point. The committee met with commissioners from New Zealand's Mental Health Commission two weeks ago.

Ms Hocking—Good.

CHAIR—Is that a model you would like to see in Australia and are there any improvements you would make? We were told earlier this morning that attaching an ombudsman's role to that model would be desirable.

Ms Hocking—I do not claim to be an expert, but my observation is that the system seems to work well in New Zealand. The commission has good representation in terms of commissioners and it does seem to be doing the job it was set up to do. I do not claim to know enough about it to know what the ombudsman's role would add to it. You set your terms of reference, I guess.

CHAIR—I ask about those people who present with dual diagnoses, such as those with drug or alcohol problems as well as other mental illnesses. My experience in Victoria is that there is a new way of thinking about this and that practitioners are now strongly discouraged from rejecting someone because they have a dual diagnosis, but there is still not a great deal out there about how to deal with it. Can you tell us what is going on here and in other states if you know about how GPs and other clinicians are dealing with dual diagnoses?

Ms Hocking—I think there would be very few GPs who would be dealing effectively with this. There would be some very good ones, but it would probably be too hard for the majority. It depends on the severity of the condition. It is certainly interesting that the rhetoric is now that there is no discouragement about rejecting. The reality, as we experience it from our contacts, is that it still does happen that, until you 'dry out' from your drug use, so to speak, you are not going to be welcomed in the mental health services and, if you are acutely mentally unwell, you are not at all welcome in the alcohol and drug services. There are certainly some good models being set up, about which I hope others will be talking to you in more depth, where you have teams that are specialists in both areas. I know there has been quite a lot of training done of drug and alcohol workers and of mental health workers about the other areas. I am not quite sure how well that is working. It is not widespread enough to really be having a big impact.

Senator HUMPHRIES—You recommend that we close all psychiatric institutions in Australia. I am reminded that the deinstitutionalisation of people 10 or so years ago was viewed as a positive concept, although the delivery left a lot to be desired. Obviously, there would be the clinical view on some people's part that closure of the institutions is not a good move and that it would deprive psychiatric services of concentrated areas of practice where there would be enough repeated procedures and so forth to create a centre of excellence, if I can use that somewhat inappropriate term in connection with these services. What consensus would there be among psychiatrists and clinicians in, say, Victoria about what should happen with psychiatric institutions? Would there be a significant body of opinion in that quarter that would agree with you that institutions should be closed?

Ms Hocking—I do not claim to speak on their behalf. I am not a clinician nor am I a psychiatrist. I think you would get varying views. Our call to close the large stand-alone institutions was very much because there was a lot that was not good about those institutions and that having the psych wards within mainstream hospitals was a more appropriate way. I am aware of the recent arguments to set up the centre of excellence, and I must say that when I read the piece about that I did see another viewpoint on that. I think there may well be a role to look at that as a pilot experience, if you like, to see how it would operate. I think the key thing is to have people treated wherever possible. In the vast majority of cases, it is possible within their local communities. It is not saying that we do not want centres of excellence, because we do; it is just that we do not need the large institutions. In most states there are still stand-alone institutions and sometimes they are being regenerated by bringing community services within the grounds of the old psych hospitals. I do not think it is the best model to follow.

Senator HUMPHRIES—What do you see as the main problem with them? Is it their size? Is it the fact that they are disconnected from other hospital services, public or otherwise? It is a culture that has grown up? What exactly is the problem?

Ms Hocking—It is all of those things. You have identified three major things. We do not need to have large bins, if you like; there should be smaller centres within local communities. Being separate from other health services means that people are seen as separate—as the other, if you like—and certainly the physical health needs of people with mental illness have been grossly neglected for many years. We know that ill health is greater amongst people with mental illness; both morbidity and mortality are increased in that group. Then there is the culture. You very much get that culture that is established in these large institutions that is not always helping.

Senator HUMPHRIES—You also talk about the need for legislative change at both federal and state levels to outlaw vilification. Can you give me some examples of vilification of the mentally ill in recent years that you feel ought to be capable of being acted against under legislation of this kind?

Ms Hocking—It is still seen as acceptable and lawful to be offensive towards people with mental illness.

Senator HUMPHRIES—Can you give me an example of where you have seen it happen? I am thinking of an example on TV—Mad Barry’s car yard or something. I suppose that might be seen as that kind of thing. Are there cases of public pronouncements by public figures or organisations that you would have concerns about?

Ms Hocking—I am hard-pressed to think of a specific example that is going to be exactly what you are looking for. Certainly it is seen as fair game these days to still be offensive and demeaning and speak inaccurately about people with mental illness where it would not be done about Indigenous Australians or people from a Muslim background or homosexuals, for example, because there is a sense that the community would not stand for it. I can think of one headline associated with an article: ‘mental illness gets hijacker off hook’. That implied the mental illness was just being used as an excuse and that there was no pain or suffering associated with having the mental illness. I would be happy, on reflection, to get something to you that would give you a clear example of that.

Senator HUMPHRIES—That would be useful because it would be difficult for the committee to recommend that we tighten up the laws if we cannot point to any cases where vilification is occurring and not being cracked down on.

Ms Hocking—I will remember a beautiful one as I am getting back to the office, but I cannot think of it now. Sorry.

Senator HUMPHRIES—That is always the way, isn’t it?

Ms Hocking—Yes.

Senator HUMPHRIES—My last question is about the mental health commission. This morning Jeff Kennett, representing beyondblue, said there was already a plethora of

organisations advocating for or providing services for the mentally ill. He felt that we should not create new organisations; we should be ratcheting up these issues to the level of COAG and so on to get them to take action. What is your answer to that argument?

Ms Hocking—I think there is some justification for that. Certainly it would need to be a very specific role that was added on to an existing organisation. We do not really need more; we have quite a number as it is. It would have to be a very clearly defined role that would be supported financially and would have some teeth—it would be listened to, in other words.

Senator MOORE—I want to follow up what you were discussing with Senator Humphries about stigma. In your presentation and in your submission, you have talked about the need to get rid of stigma in the community. I am interested to know whether you have any suggestions about how we do that, apart from legislation. What else can be done to remove that? From your point of view, what is the voice of consumers in the genuine discourse around mental illness in Australia like now. It is not really mentioned in the report—although I know you do a lot of work in that area. How should it be used and how can voices be heard in the general discussion about mental health?

Ms Hocking—First of all, the destigmatisation program needs to be a community-wide national program using the mass media. You would know much better than I that you can influence people within Parliament House through the mass media as well as any other way. It does need to be carefully designed. Years ago there was a very good initial campaign—the television ads that you may remember. People still talk with me about those; they did sink in. It is just there was never anything to follow up. So there was not that sustained action. Again, in New Zealand they have had a very large-scale national campaign to do that.

I think that what we need to do is not just to talk about mental illness but also to talk about the range of people with mental illness and the range of impacts on their lives. The first stage that we did here probably 10 or 12 years ago did not help those folk who had an ongoing disability with their illness because it was more or less said that everyone gets back to normal, gets on with their lives and there are no apparent signs of mental illness thereafter. To some extent I think what that did was to further stigmatise those folk who had a disability associated with their illness because there was an inference that they were too weak to get ill in the first place and then they were not strong enough to get back to where they were to start with. It was really damaging, horrible stuff. It requires money and skills in that sort of area. It requires contact with real people with mental illness, not actors. We have fabulous groups of people who can speak for themselves; we have to hear from them. It has to be ongoing. It has to be top down and bottom up—at local community level as well as the mass media.

Your second point about the role of consumers is incredibly important because we have to hear from the people who are central to this whole issue. We have to hear about them, their lives, what helps and what they think is going to be better. I know from talking with many consumers that they feel that things have gone backwards in recent years and that they do not have the same opportunities to speak directly with policy makers, as was the case a few years ago—others will talk about that later this afternoon—and it is probably both at state and federal level. I think we have gone backwards. It is something that needs to be strengthened. Certainly, at the moment when consumers and carers want to speak at the federal level, they speak through the Mental Health Council of Australia. There is not that same opportunity to speak outside that forum.

Senator MOORE—I am interested in the token consumer voice. There are a lot of things written now which demand that there is consumer participation and I would like your view on that.

Ms Hocking—It is very easy to write it in. I think ‘tokenistic’ is a very good term. I think that real, meaningful, genuine stuff is rarer than it would seem from the documents. I think that is really short-sighted.

Senator SCULLION—I want to talk about the common theme of the importance of destigmatisation. You have said that you would like to see regulation cover some of the issues surrounding vilification. I have also heard some evidence from others this morning about the way we describe people. If our vision is to have the wider community quite comfortable with the issues of mental illness, as you have asserted, we need to be very careful about the words we use. It seems you are saying that we need to be particularly politically correct about it—in fact, we even need to regulate it. I have difficulty with using that political correctness and having an outcome that people are very comfortable with. People have said they are quite comfortable with being called batty. Everybody has batty aunts. I am comfortable with the word ‘batty’ but ‘mental illness’ frightens me. Is there an axe involved? What does mental illness mean? We have the word ‘consumers’ now too. I thought they bought cornflakes. We used to call them patients when I was younger but now these words are politically correct. Consumers or customers have told me today that they prefer to be referred to in more vernacular terms—I certainly agree with their sentiments. People are more comfortable with it and if people are more comfortable discussing the issues of mental illness, maybe that is the way to go, but it seems to be at odds with what you are asserting.

Ms Hocking—It may be an evolutionary thing. I think that very often it depends on the intent with which the words are used, who uses them, in what context, for what end and if they are used as affectionate terms. I think people who have a mental illness can use terminology that people who do not have a mental illness do not use. It is a matter of respect. Whenever language is used, it should be used respectfully. Others will speak more eloquently about that afterwards. We just know that people who are affected by mental illness who we hear from are really sick, sore and tired of being described in terms of their illness, not in terms of who they are as a person. Being called a psychotic, a depressive or a schizophrenic dehumanises who you are.

If you have had decades of being dehumanised, after a while you just get a bit fed up with it. I am trying to think of some terms for males that you might react to if I were to use them which stereotype and brand you in a way that would not be accurate. Decades on, when people have been treated respectfully and with dignity, they may say: ‘Look, call me batty. That is fine; I’m not going to worry about it.’ But if it is always used in a derogatory sense, so it is an insulting term, the association is not positive. You may say ‘batty’ and use it very affectionately; others may not. We are not going to let this one drop. I think the use of the word ‘consumers’, again, is because that is how people say they would like to be referred to. Not everyone will. But, again, if there is a process where that word comes up, it is just respectful to use it.

Senator SCULLION—Thank you.

Ms Hocking—There is no short, easy answer.

CHAIR—We will leave it on that note, Ms Hocking. Thank you very much for your submission and for appearing today.

[2.52 pm]

COLLINS, Ms Isabell, Director, Victorian Mental Illness Awareness Council

WEBB, Mr David Robert, Chair, Victorian Mental Illness Awareness Council

CHAIR—Welcome. Please state the capacity in which you appear today.

Ms Collins—I am the Director of the Victorian Mental Illness Awareness Council, which is the peak consumer organisation in Victoria for people with mental illness or emotional problems.

CHAIR—You have lodged with us a submission, which we have numbered 267. Are there any amendments or additions that you want to make to that document at this stage?

Ms Collins—No. I could provide many additions but, given that there have been inquiries in this country ad nauseam, I will not. I had a great deal of difficulty doing it because, with the greatest of respect, I do not have much faith that anything much will come out of it for people with a mental illness. But I do have an opening statement.

CHAIR—We hope to prove you wrong. I invite you to make a brief opening statement, after which we will go to questions.

Ms Collins—There are many things that need to be changed in the public mental health care system; none can be achieved without adequate funding. Unfortunately, in this country, including in Victoria, we are bereft of positive leadership where people come first. There is what I would regard as a political obsession with doing what is popular, which is not necessarily about doing what is right. Ethical government has clearly taken a back seat. When you have so many preventable deaths through suicide, largely because people are unable to access appropriate and adequate clinical and non-clinical services, and governments know about it and do just enough to look like they are doing something, then what else can one say? When we as a community accept the abuse and neglect of our fellow citizens, including our new citizens, then we, in my view, are a nation in ethical trouble.

Prior to the last Victorian budget, our current government indicated that mental health was going to be a priority in this year's budget. That is because we were left out of last year's budget. This gave us all hope. However, my hope was taken away when, just before Christmas, a politician told me that another politician had told him: 'Given that there has not been much bad publicity about mental health of late, it looks like we won't have to put as much money into mental health as we thought we would have to.' It is a sad reflection on how lacking our politicians' ethics have become when publicity is the major guide to decision making, even when members of their community are dying through a lack of funding and service neglect. Additionally, another politician was reported to say that, given that the government has overspent on the Commonwealth Games, the funding for mental health would be reduced.

Press reports of overbudget spending in a number of government projects confirmed that mental health probably paid a very heavy price in this state for that. Indeed, if you look at the

additional funding that was provided for mental health in this year's budget, you see that it only covers the areas where the government received bad press, and the rest of us have been neglected. In fairness to the current Labor government, they have been a bit more responsive than the previous Liberal government. However, they have been in power long enough to have done a great deal more than they have done. Put simply, the impact that a lack of funding has on service delivery is to prevent clinicians from complying with not only their professional standards of practice but also the objects and other components of the Mental Health Act and government policy. We look excellent on paper in Victoria, but in practice we should be ashamed of ourselves.

As someone who worked as a general nurse for 25 years, I know that when you are busy you mindfully cut corners for a day. Unfortunately, the work pressures in mental health have been so underresourced for so long that the cutting of corners has now become standard practice, and it would not be an exaggeration to say that it is costing people their personhood and their lives. For example, you could pick up any medical file in this state and not find a single sentence about how the patient feels. You may have somebody who was suicidal, and the risk assessment is to ask whether they are suicidal and whether they have plans and to sight them every 15 minutes. In other words, if their head is on the ward and you can sight it, that is all you will do. Yet it is the feeling side that will drive people to kill themselves. But we do not even bother to check out how the patient is feeling.

Put simply, the current standard of practice is to contain people with medication and then discharge them. That is all we do. Any expression of concern a patient may make about how they are being treated will be pathologised. In other words, they will be ignored. Indeed, even our health complaints commissioner has been known to ignore components of the Mental Health Act and evidence in medical files to cover up outrageous standards of practice.

To give you an example, this was all in a patients' medical file: being stripped naked and being left completely and utterly naked without any bedding or clothing, with a male nurse sitting outside the room watching through the window. The act is very clear. The act says: 'must be provided with appropriate bedding and clothing under the circumstances'. Just recently a judge—it had to go to court—found that that was illegal. But that is what that person had to do to get natural justice. She made a complaint to the hospital and did not get anywhere. She made a complaint to the health complaints commissioner and did not get anywhere. She came to me requesting advocacy. I produced the evidence in the files that demonstrated that the act had been breached and her care was disrespectful. I was told that I was one of the worst advocates around—and that was spread—because I had produced that evidence in the file which demonstrated that the director of clinical services had lied in his response. Nobody has ever been made accountable for the fact that that girl was denied natural justice, and I certainly have not received an apology for being right. When they do make complaints, people are constantly denied natural justice, through a pathologisation of their complaint.

I have worked in mental health for 14 years, and as an advocate for the last 12 years, and to me the outrage over how people with a mental illness are being neglected and how they are being treated, due to the lack of community and service providers, is of major concern. Pre every budget we have hope and post every budget we have our hope taken away from us. To me this last budget was the straw that broke the camel's back. Clearly, if things are to change we are going to have to fight every inch of the way. Unfortunately, that is the way things are now,

because we have lost sight of what the basics are. No other patient group would have to endure such disrespect and neglect, and if one has to fight to get governments back to the basics then so be it.

CHAIR—Would you outline for the committee how your organisation receives funding.

Ms Collins—Keep in mind we are a statewide service that provides individual advocacy, group advocacy, mutual support, self-help and education. We get funding from the state government for four full-time staff—me, an administration assistant, one advocate and an information officer. The Commonwealth government provide us with funding for one staff member. We got \$20,000 from Reichstein to employ somebody part time to do some systemic advocacy, but that funding was only for a year.

CHAIR—Do you advocate on behalf of individuals as well as the sector as a whole?

Ms Collins—Yes. We do individual advocacy. We have 82 consumer groups across the state. We meet with those groups on a monthly basis to see how they are going and to take up issues for them—if they want—as a group. That is as well as people ringing in requesting advocacy.

CHAIR—You are critical of the health commissioner for not upholding the act in the case you cite. What would you like to see in terms of a better system? Are you arguing that the health commissioner did not do her job in this instance? Do you think there should be another kind of ombudsman specifically for mental health or a commission like the one in New Zealand?

Ms Collins—In fairness to the health complaints commissioner, I have worked in the Office of the Public Advocate, which is an independent agency, as an advocate, and I do know that it has covered up in the past. I have had cases before the Ombudsman's office in the past; again, evidence has been ignored, so the health complaints commission is not the only organisation. I have known the Office of the Chief Psychiatrist in the past to cover up, even though under the act they are responsible for standards of treatment and care. In reality, they are there to protect the minister. My view is that it depends on an individual and that we should never have to rely on an individual. I think what we need to do is look at legislative changes to ensure that accountability provisions are put into acts so that when people do not do their job it is easy to make them accountable. We do not have any accountability clauses.

For example, when you are dealing with people with a mental illness, you find they get very stressed very easily and can become unwell. To give you a practical example, I once had come to me a consumer who indicated that she, as an involuntary patient, had been raped by another patient in hospital. This had happened two years previously. She was still very distressed about it. What happened is that the police came in and they indicated that, because they were both involuntary patients, neither would be good witnesses, so there was no point in having charges laid. After we had seen to this person's needs and got her off to a CASA, I indicated that, in my view, she had a legal case for negligence: they were both involuntary and neither of them were protected while they were patients. So we went to a lawyer, and she had a good case. It got to the point of a compulsory meeting at which it was stated that the service was going to fight it every inch of the way because if this case were won it would open up the floodgates—which it would have. My client caved in—she just could not cope—and the case never proceeded.

To make a generalised statement, I think many people rely on making it difficult for people to carry through with their cases—they rely on the person's illness and the anxiety and stress. If we are serious about people with a mental illness having rights and having those rights respected, then we need legislation which ensures that the people who are responsible for overseeing that legislation—seeing that the law of the land is complied with—are made accountable when they do not do their jobs.

In relation to the Office of the Public Advocate, where a case was covered up, the reason for that was that they had put in for funding for additional staff to the justice department and it was felt that if they proceeded with this particular case they would not get funding. The health complaints commissioner prior to this one made critical statements publicly and she was put on the mat by the minister for that—that occurred under the previous Liberal government. I have worked in the system long enough to know that there is no such thing as an independent service or agency in this country. The high-profile agencies, especially, rely on their relationships. We do not take account of the human element of people wanting to have coffee with the minister and senior bureaucrats. We take no account of those sorts of things—if that makes sense. People become friends with the people they hang around with. That influences decision making. The negative side of that is that it takes away people's ability to receive natural justice.

Senator HUMPHRIES—Earlier on, insane australia gave evidence about what they saw as a need for a commission or an inquiry into abuses in the mental health system, and I asked them to take on notice the giving of examples of abuses within the system. It was suggested by them that your organisation might have some examples of that kind of abuse. You have cited one case at least in the evidence today. Do you have other cases that you could tell us about—

Ms Collins—I certainly could.

Senator HUMPHRIES—or, alternatively, record on paper and forward to the committee separately?

Ms Collins—Yes, we could. There are daily abuses. I will give you my background. I was a general nurse who was happily minding my own business when I was seconded 15 years ago into the mental health branch to, as they put it, 'help clean up psych services'. I had not been exposed to people with a mental illness apart from those who had come in for the occasional medical or surgical issue. So I was involved in the statewide ministerial audit that went into all of the psychiatric institutions. To say that that had a profound effect on me would be an absolute understatement. Every time—even now—that I think about it I get shivers. If someone had said to me beforehand, 'This is the way we treat our mentally ill patients,' I would have said, 'There is no way known that in Australia this would happen.' Initially I said to myself that these were psych nurses and that general nurses would never treat their patients like this. Then I started running into nurses that I had worked with who I knew were good nurses and I would say, 'How on earth can you do this?' They would say, 'What do you mean?' I would say, 'To be part of this—it was shocking.' They would say, 'What do you mean?'

To cut a long story short, at the end of the audit we were given an instruction to falsify the audit, because it was right on the cusp of the election. The exact words were, 'Remove anything from the audit that can be sensationalised'—that is, delete the number of rapes. I was the only one on the team who refused to go along with that—I had been the person who had interviewed

the patients about their experiences. I indicated that not only would I resign but I would go public. One does not survive a system—and when you work in the health department as a bureaucrat—when you make that kind of stand. However, I made that stand and I spent some eight months later unemployed, walking the lounge room, asking myself: ‘How did this happen?’ It is not that the people who work in the system are bad people; they are not.

But this is my conclusion and it is something that all of us have to keep our eye on: we are all creatures of habit. If we see something often enough, we just simply cease to see it. If we hear something often enough, we cease to question it. That is where I think bigotry and prejudices and all of those things come in. If we do something often enough, we do it without thinking. We constantly throw people into seclusion and strip them naked, even if they have a history of sexual assault, without any consideration of the impact that might have on them. We only ever pick on those or treat dismissively those in less powerful positions than ourselves, and if we see abuse we tend not to get involved unless it is somebody we love. That is the guiding principle.

For argument’s sake, take consumer participation. We asked our 82 consumer groups, ‘If you could wave a magic wand and change something about the system, what would you change?’ They say, ‘Attitudes and stigma.’ We have been saying this for years, at a Commonwealth and a state level. Consumers tell us that the stigma and the culture within clinical services and psych disability support services—contrary to what you just heard—are worse than anything they will experience in the general community. They have been saying it for years. All the things that consumers raise as issues that are important to them are the things that we have not addressed. Why? Because we will have to take on the people who have positions of power in mental health and government. I can give you—and I am happy to do it—example after example of the most outrageous treatment of people with mental illnesses.

Senator HUMPHRIES—You will do that in writing?

Ms Collins—I will, yes.

Senator HUMPHRIES—Thank you.

Senator FORSHAW—The picture you paint is very stark and gloomy. One point you make at page 3 of your submission is the tragic level of preventable deaths through suicide. You speak of:

... an average of 350 reportable deaths a year, that is to say, people who have died while in the care of the public mental health care system.

You then go on to say:

... the Director of Mental Health, Dr R Vine reported that 21 people suicide annually within 5 weeks of discharge from hospital.

Could you expand on that last point in particular? As a literal reading, one could say that people are being discharged early. You have painted some pretty stark, rather disturbing pictures of the treatment some people are getting in hospitals or psych institutions. Could you expand on that situation about discharge? What is it—a lack of services in the community? Is it that people are being discharged too early? What is the problem?

Ms Collins—On paper, we look really good. We have crisis assessment and treatment teams, for example, which consumers refer to as the ‘can’t attend today teams’. People will ring up and say: ‘I’m feeling at risk. I’m feeling suicidal. I need some assistance.’ The CAT team will say, ‘If you’ve got that much insight you’re not sick enough to be admitted.’ That may very well be so, but what happens is that they are left to deteriorate to a point where they may very well lose insight and they are at extreme risk. Then you have to involve the police. The person gets handcuffed, they are taken to hospital against their will and they try and express concern about that. We do not humanise what they are saying as a normal response that every adult on the face of this earth would have under the same circumstances; we throw them into seclusion and we medicate them off their face. The nurses remain in the office. These people are involuntary. They meet all of the criteria of the act. Where are the clinicians? In the office. Where are the patients? Out in the ward on their own.

Then they will be discharged because of shortages of beds. Certainly psychiatrists have said to me that they are constantly in this ethical dilemma where they have somebody who is really sick and needs admission to hospital and they have somebody in hospital who is still sick but not as sick as the one who needs to come in. They have to juggle and take these risks. What happens is that they do take the risk. They send them out into the community where there are no supports for them.

The risk assessments that are done, in my view, are absolutely and utterly negligent. They take no account of what the person might be feeling. As long as they are not hearing voices and all that sort of stuff, it is fine. There is no consideration of the fact that, if you have a diagnosis of a paranoid schizophrenia, for example, and you think somebody is after you and is going to kill you, the paranoia is not real but the feeling side of it is extremely real. Yet we constantly ignore it. So it is a lack of services. People either cannot get in or, if they get in, they are quickly out—

Senator FORSHAW—Are you saying that, even where the service may be available, there is actually a breakdown in the relationship, if you like, beyond referral of a patient who is discharged?

Ms Collins—Yes.

Senator FORSHAW—I am from New South Wales, so I do not understand the Victorian system as well. But I find it strange that a patient could be discharged and, if that person is in need of ongoing service, some arrangement is not made with the local area mental health team or the community based service that is generally attached to the hospital.

Ms Collins—What they are doing is turning people away. You have case managers who should be the ones who coordinate care and treatment. Consumers tell us time and time again that they go, say, once a fortnight to get the needle in the bum. They will ask, ‘How is it going?’ The consumer will say, ‘I’m having dreadful side-effects from my medication.’ They will reply, ‘See you next week.’ They cannot get in to see their case managers. Some of them do not even know who their case manager is. It is a resourcing issue. We will never change the practices and humanise care and treatment until we get the resources. However, resourcing is not the only answer.

Senator FORSHAW—Can I try to take you, if it is possible, to the positive side. Is there a model or an example that you can point to which is working—say, here in Victoria? You have given us the horror story and I do not argue with that. But, in your experience, is there somewhere that you can point to about which you could say, ‘Here is a place where the service is working well’? Is there a particular model that is working that all of the others should emulate?

Ms Collins—To me it is not about the model. We have a model. It has never been funded adequately enough so as to implement the model to its full potential. That is the issue. It has never been funded. There are certainly models, for argument’s sake—

Senator FORSHAW—I was thinking of a real-life model in a centre or a hospital or somewhere.

Ms Collins—I have to say there are some lighted beacons out there. You may be on a ward and you may see somebody who is very unwell. You would stand there and think to yourself, ‘Bloody hell, this is going to be it.’ You see that lighted beacon talk with that patient, empathise with them and avoid seclusion. You may be on a ward the following week and see something nowhere near as bad as that and yet they are off to seclusion. It is being left to individuals. I do not want to suggest that there are not the lighted beacons out there. I do not want to suggest that most people do not care. It is that habit of practise. I say to people that nursing is a bit like being Catholic—once a nurse, always a nurse, even if you do not practise.

Senator FORSHAW—And you can always go back to it!

Ms Collins—Yes. As a general nurse I have to tell you that nurses have lost sight of the basics. In psych nursing all they are doing is carrying out the instructions of the doctor in many instances. They have lost sight of what nursing is, which is to nurture and take care of your patients. These are habits of thought. Everything is pathologised and not humanised. But, in order to be able to change that, you need the funding, the resources and the safety.

We have a culture of protection in this state, as I have no doubt we have in this country. The government want to be protected from criticism and they place pressure on the bureaucrats, who want to be protected from political criticism. The bureaucrats place pressure on the managers because it will make them look good, and the managers place pressure on the staff to cover up. We have to look to a culture where we can have open, honest discussions about what works and what does not work. What we are doing is using a very defensive reasoning process in problem solving: we address the results of the problem rather than the root cause. One in five people have a mental illness now. A major cause of depression can be the way you are treated—your experiences of life, discrimination against you and things like that.

I will give you a practical example; it might make you feel uncomfortable, but it happened a long time ago. There was an allegation made about George Pell, and the Prime Minister, before any investigation whatsoever, came out in support of George Pell. Our phones rang hot with calls from distressed consumers, saying, ‘What does that say?’ These were consumers who had experienced childhood sexual abuse and that message was being sent to them. It made me think, ‘What about the kids who are watching television right now who are being abused?’ The same thing happened when people went after Justice Kirby. I had two young homosexual men on the doorstep the next day, very distressed, crying and suicidal.

We have to get back to the basics and to education, because to me things like prejudice come when we are kids, when adults teach us stuff that we as children do not have the capacity to question. The fact of the matter is that people have darker skin because they have more melanin in their skin. People have Asian shaped eyes because they have an extra skin fold in their eyelids. As adults not a single one of us gets a choice about the food we like, the clothes we like, anything relating to personal taste. To me homosexuality is no different. It is a matter of taste, not choice. I do not get canned because my favourite vegetable is the potato.

We have to revisit all of these things because people are killing themselves as a result of these prejudices, and particularly when the leader of a country is not even thinking about these things. On the one hand we are pouring millions of dollars into depression; on the other hand we have these prejudicial remarks by politicians who will not show leadership and talk about these things openly and honestly and re-educate the community about these things. As for religion—good God almighty! I am no expert, but if you read anything on the history of religions they are all fundamentally the same. Catholicism and Islam are nothing more than factional breakaway groups from Judaism. We have to start looking at the facts and try to re-educate people so that we can stop people from killing themselves. Does that make sense?

Senator FORSHAW—Certainly. We hear what you say.

Ms Collins—It is you the politicians who have to take up that mantle and be less concerned about whether you are going to win votes and more concerned about saving people's lives and making this a much more emotionally comfortable place for all members of society to live in.

Senator MOORE—I do not think there could be any questions, Ms Collins! Do people listen to you, Ms Collins? You have been fighting this fight for a long time and it obviously consumes you; do people listen?

Ms Collins—No, I do not think so. The feedback I get is that people respect me for my frankness, ethics and all that stuff, but at the end of the day I only run a consumer organisation. While I do get treated for depression, I have never been in the public mental health system, but as the director of a statewide consumer organisation I have certainly had some experience with the stigma that consumers experience, because in the health system the mental health patients are the least important people, and I experience the same thing from time to time.

In my individual advocacy, people listen because I will not cover up for anybody. We have had some great successes in relation to individual advocacy but our ability to influence in a systemic way is thwarted by our staffing. Because we have to see to people's needs all of the time, our ability to take up things in a systemic way, which is what, as a director, my role should be, is quite limited. To some extent, I would say no, but to some extent, because of our work pressures, I have not been able to test it fully.

Senator SCULLION—Thank you very much for your very informative input. I was interested in drawing out the balances that people obviously have to find between duty of care and trying to minimise the impact on other patients. You said that the easy answer is isolation for some but perhaps not for others in different circumstances. Obviously, duty of care is about ensuring that the right of freedom for one does not impact on the right not to be raped of another.

This is the great balance of rights. Do all those things generally happen in an institutional model of some type rather than the broad community based model that has been spoken about today?

Ms Collins—That would be an assumption and I think an incorrect assumption.

Senator SCULLION—Do you have any comments on whether or not the issues of treating people with mental illness of any type which are associated with putting them all in the one place to treat them are going to continue to impact on those rights?

Ms Collins—I think part of it is in the assessment and the assessments are fairly shoddy. If somebody comes in to hospital and they may be at risk, it is about sitting down and interviewing that person about how they feel. If they are feeling unsafe or they are going to be vulnerable to abuse, you talk with them about the strategies that you might implement to ensure that they are safe and you actually write it up and implement it rather than leaving it on a piece of paper which probably gets ignored. In relation to the imposition of enforced treatment, I am not in agreement with my colleagues sitting behind that there are not instances where you may very well have to impose your will onto somebody. But it is overused and abused.

For example, the person may be in the community sector. To me one of the roles of a case manager is to establish a plan of action with the person so that if when they are unwell they become noisy, a bit exuberant, aggressive or whatever, they are asked how best to handle that situation. Would it be better for them to be taken aside and have someone sit down with them; would it be better that they have someone like a loved one there? The person should be asked about the strategies that work and then those strategies should be put in place in hospital. None of that ever occurs. I used an example in my submission of a woman, I sent you photocopies of photographs of her bruised body, which occurred this year. Throughout her file, before her first admission, it stated that she had head injuries and as a consequence of those she had developed noise and light sensitivity. She went to the nurses station and asked for cotton wool to put in her ears. They said no, it was not appropriate and would not give it to her. She came back twice to ask for something and was told no. There was nothing in the care plan about assisting her. Again, prior to her admission, the file stated that she was terrified of ever having to be admitted to a psychiatric unit. Again, there was nothing in the care plan where anybody had asked her what would make her feel safer or asked her what could be done.

Interestingly enough, in the general hospital, they did. They said she had to go to a psych hospital because they did not feel equipped to handle her, but their actions were completely and utterly respectful of her anxious state and stuff like that. To me, a lot of the seclusions and involuntary treatments and things like that have a lot to do with how people are treated. If you are an adult and somebody is telling you that you have to do something that you do not want to do and people hold you down and force you, you are going to be fairly pippy. The only way patients have to fight back is to refuse to take their medication. Why on earth would an adult cooperate with another adult who treats them like their feelings are totally and utterly of no consequence whatsoever? We are asking people with a mental illness to accept less than what any normal adult would accept.

I should tell you that I go into Thomas Embling Hospital on a regular basis. Contrary to what the *Herald Sun* said when it talked about these people being the most dangerous in society, they are lovely people and I will have them in my home any time. It is an absolute tragedy that most

of them are in there because their families could not get them the support they needed so they did commit a crime—in some instances, horrible crimes. Once treated, they are so regretful of the things that have been done. Governments have never been made accountable for the fact that it squarely lies with them that these people could not get the services they needed so they are locked up in there for years.

CHAIR—Thank you very much for your submission and presentation. Mr Webb, you indicated earlier that you might like to say something else to the committee. Do you still wish to do so?

Mr Webb—I put my hand up because there have been a few requests for some sort of concrete evidence, case studies and testimonials. It would be nice if there were more of these. Senator Forshaw asked about the discharge. I want to give a brief snippet of my own story. Back in 1999, I attempted suicide on a Thursday night. On Friday, I told my doctor, and he wanted me to see a psychiatrist. I saw the psychiatrist. He certified me. I was taken to Royal Park Psychiatric Hospital and locked up. I did not care at the time. It was fairly late on the Friday, so I was too late to see the doctors on that day for assessment. I did not know at that time that the Mental Health Act requires that you must be assessed within 24 hours after being certified. I was assessed on the Monday morning, it being the weekend—and I find the notion of a business day at a psychiatric ward very peculiar. It took about 15 minutes with the psychiatrist, the nurse, the social worker and maybe some other people.

On the strength of that assessment, the psychiatrist judged that I suffered from what he called existential depression and that I did not need to be there. I had attempted suicide just a couple of nights before. He told the social worker and the charge nurse to arrange for my discharge. That was it. The psychiatrist spoke to me about where I would go on discharge and whether I had somewhere to go. I did not have a place to go as I did not have a home in Melbourne at the time. He spoke to the social worker and said, ‘Help him find somewhere to go.’ I left that hospital with the phone number for the emergency accommodation of the Salvation Army. That was the discharge support that I got a couple of days after a suicide attempt. People tell me that would not happen these days, but I am not sure. I am one of the fortunate ones. There are a lot of people that have been through that experience and they have gone straight to the nearest railway line to jump under the first train. We see that in the data. We know that. I just wanted to throw that in as a testimonial that I can give from my own experience.

CHAIR—Thanks for telling us that.

Proceedings suspended from 3.35 pm to 3.47 pm

PETHICK, Ms Leanne Therese, Founder and Chief Executive Officer, depressionNet

CHAIR—Welcome.

Ms Pethick—Thank you very much and good afternoon.

CHAIR—Thank you for coming. You have given us your submission, which we have numbered 475. Do you wish to make any amendments or additions to that submission, at this stage?

Ms Pethick—Do you want the little ones, the typos?

CHAIR—Probably not. I invite you to make a brief opening statement, after which we will go to questions.

Ms Pethick—As I have not done this before, I hope you will bear with me. I assume that you have had a lot of people who have not done this before. Particularly given the nature of my submission, what I would like to do is put context around where I come from when I come to the table. I understand that we have 20 minutes here.

CHAIR—Yes, we have scheduled about that long. You just take whatever time you need—but the shorter your opening statement is the more questions we can ask you.

Ms Pethick—I think this is particularly relevant because it is the background to the power of some of the subtle things. My historical experience is that quite often, in a document of the nature of the one that I submitted or on the sorts of issues that I submitted to the committee, the reaction I have had in past lives has been ‘Well, what’s the point?’ My formal qualifications are in applied science—I came through the engineering faculty at Melbourne; apparently, we are not supposed to have any human characteristics coming through there!—in metallurgy, and later I did applied science and mathematics and majored in statistics while my girls were little; I have two daughters. I am a mother and I care for my two daughters. I have chronic depression, which is effectively managed. I had it for 30 years before I found out I had it, and it was pretty well effectively managed for those 30 years. I then came to a major depressive episode, which was not effectively managed for the first little while.

I have formal qualifications. I work in a professional capacity as a carer in the mental health industry, and I am a mental health consumer. That makes me ‘confused’. It is like doing the Myers-Briggs test 10 years ago and being told you are ‘weird’! My career in paid employment started as a telemarketer with Telstra during the deregulation of the telecommunications industry. I started there part time. I did not really want to work; I was a single mum at that stage. Within the first 12 months, that national telemarketing centre went from having 12 people to 1,200 people. That was phenomenal growth for a business, and a whole range of challenges came with it. In that 12-month period, I was a telemarketer for two weeks, team leader for four weeks and group general manager for six weeks. Then I took over the reporting. Somebody found out I had a degree in mathematics and said, ‘Leanne, do the reporting.’

Towards the end of that first year, I spent 11 months working on recognition and reward with a woman from the United States. The relevant issue there is that I learnt from her—and it was certainly proven through that experience—that people do not always know what they want. More importantly, people will often say they want something when in fact they want something else. This woman said that money would not motivate behaviour. When we asked the 1,000 staff in the telemarketing centre, ‘What would you like?’ they said they wanted money, when it was in fact recognition that drove behavioural change within that organisation. It was a very powerful learning experience for me to go through that, to see it happen and to be a part of that.

The second relevant issue for me was that I would go out to meet the teams—I would call these meetings ‘stonings’—and I was the victim. These people were in groups of 20 and 30. They were working their butts off in an organisation that had grown very quickly, and they had a lot of issues which their line management did not know how to address. The recognition and reward program was handed over to us from other areas of Telstra, and it was totally inappropriate for that environment. My role was to say: ‘It is not perfect; stop expecting it to be. Let’s look at what we can do it. Do we say that because it is not perfect we should stop it altogether? Do we say that, because somebody might get more than is fair and somebody might get less, everybody should get nothing, or do we work with this together, look at what we can learn and how can we improve it, get some recognition along the way, and then put together a plan for the way forward?’ That is exactly what we did—and we got the 1,000 people, because a lot of them had started as telemarketers with me and still wanted to be telemarketers, and it was very much a case of taking ownership.

From there I went to corporate affairs and managed research on service quality for Telstra. I was then asked to manage operator assisted services through a very important time for 013 calls—we all remember 013. At that time, with regard to productivity, the average 013 call took 64 seconds. Because of the sheer volume of 013 calls that went through, a saving of one second on an 013 call would save Telstra \$8 million a year. They had a very strong productivity drive. What actually happened, though, was that, as their productivity went up, their service quality went down. Telstra obviously has external obligations to ensure a certain level of service quality, so there was massive panic within management. They said: ‘What do we do? We’ve got to get service quality down.’ They just assumed. What they did was lower their service quality levels and come to an agreement with the Telecommunications Industry Ombudsman.

At that same time I just had a gut feel that that was not right, that it was not service quality versus productivity. I spent four weeks out having chocolate cake which, as a researcher and a statistician, I know is an important sanity check. When you go and sit in the call centre at Roma and you have chocolate cake with Sue and Cindy and Mark you realise that here are three generations of one family doing 013 calls. We all know that taking 013 calls can be really boring. For people in Roma in outback Queensland, in Katanning, in Broken Hill, in a lot of these places, it is one of the major opportunities for employment in town. People take a pride in their work. They want to. They are not stupid. They know that if they do not get their productivity up, with competition coming in, they are going to lose their jobs. They have ownership of it and they want to do a good job for the person on the other end of the phone.

I took that back and went to my line manager and put together a proposal for how we could not only increase productivity but also increase service quality at the same time. He looked at it and said: ‘There is nothing there. Don’t worry about it. Go back and do what you are supposed

to be doing.’ I then got the employee opinion surveys from corporate headquarters and took them to our group general manager who told me that she had just paid \$7 million to have consultants—out-of-work engineers—come and tell them exactly the same thing. Really, all it takes is going out and sitting down with the people and having chocolate cake.

So that is my history. During my length of time at operator assisted services I had my major depressive episode. Nobody at work knew and when I finally owned up to being a fruitcake people said, ‘Don’t be stupid; you cannot have depression.’ Because I had been so ignorant about depression beforehand—and I hate to think that I was so ignorant about anything—when I went with stress to my doctor and she said that I had depression I said: ‘Don’t be stupid. I am not a neurotic, middle-aged female who sits around and pops Prozac and watches *Days of Our Lives*.’ I had obviously read some article about pill-popping and that was my perception of people who had depression. I did not know anybody that had depression or any other mental illness. That was only seven years ago.

I did all the wrong things. Being particularly intelligent, I filled the script and then threw it in the rubbish bin and decided that I could do this myself. I had had all the management training, all the personal development training and I could get through this and I did not need drugs and, as sure as hell, I was not depressed. I never took any time off work.

Some two months later, after doing an absolutely brilliant presentation at work, a friend came and picked me up off the floor. I had just realised that I must really be crazy, because I decided that I was going to take my own life. I decided a split second later that, bugger, I could not because my children were so neurotic, having been brought up by me, that they could not survive with anybody else and I would have to hang around for them. I hated them. There was no such thing as a problem, only an opportunity. It was when that thought came at the end of realising that I could not take my life that I thought that I really was crazy. If I could think that there was no such thing as a problem, only an opportunity, at a time like this then I needed serious psychiatric help. However, it was really in that moment that the concept of depression was born. One of my weird life philosophies is that there is no such thing as a problem, only an opportunity and let us go looking for it. There lay the seed for why on earth I had done everything wrong and had been so stupid.

The friend helped and took me back to the doctor. During that time I never took any time off work apart from two weeks annual leave, which of course everybody does in summer. I then assumed that everybody was as ignorant as I was about depression. People said that I could not have depression and I would say: ‘I know, it is not what you think it is. It is this over here. What do you want to know about it?’ I had overcome the stigma that I felt about it and I just assumed that the other poor buggers were as ignorant as I had been.

In fact that was not the case and I found that in my workplace not only was I not the only one to have depression but depression sufferers were everywhere. They came out of the woodwork. I became ‘Miss Popularity-plus’. People wanted to have coffee, lunch et cetera. I had drinks after work. I had only been there five minutes and they were saying, ‘Are you a fruitcake too and do you want to talk about depression? Is it yours or is it somebody in your family?’—I do not know about the fruitcake bit but—‘Where is your psychiatrist? Where are you going for this? What are you doing for that?’ We were having ‘fruitcake’ morning teas within a year at OAS.

At the end of that year, while we had these discussions, basically what we came up with was the idea for a bucket of information—wouldn't it be great if there were a bucket?—instead of all of us going out there and finding out all this really weird information and going to two separate specialists and being told not only different but conflicting information. This was at a time in our lives when we poor buggers needed to deal with something that was really causing us a lot of stress, impacting our family, our work and everything else and we had less capacity to cope with it. One of the most frightening things for me was that I was a competent, capable human being and when depression came along I was not sure that I could trust my GP. How did I know that my GP, whom I had trusted with my daughters' lives for the last 10 years, knew what she was talking about? That in itself is very frightening.

The idea was for a bucket of information: wouldn't it be great if there were a bucket and we could all put what we found into this bucket? Only a few of us would need to go out and liaise with experts in the area. If I wanted to know about slapping fish, they would go out and find the best information on slapping fish. Somebody would try slapping trout and say, 'No, it was hogwash, but it was great for my arthritis.' Somebody who had tried slapping herring would say, 'No, slapping herring is absolutely useless.' But they would put the information in there, so that if I am going to try slapping fish—before I try St John's wort, before I try medication—that might be part of my journey, rather than saying you should not. Information and education are not going to make human beings do the right things. Otherwise, why does anybody still smoke? There is nobody out there who thinks that smoking is actually healthy for you.

That is how depressioNet came along. I was then moved into Telstra's online channel. At that time, I said, 'Oh, my God.' I had this terrible feeling the universe was going to make me make this really dumb internet site. Eleven months later, I walked into work one Monday morning and a colleague of mine who I had been trying to get along to see his GP about the way he was feeling had hanged himself on the weekend. I said: 'Oh, bugger. All right, I give in. I'll do it.' I intended to do it for four months; within four months it became the No. 1 ranking health and medical information site in Australia. Not only was online channel and operator assisted services riddled with people with depression, but they were out there and they were everywhere. We were hiding.

That is the history of depressioNet, which is really important because the philosophy behind depressioNet is not about changing the world out there; there are beyondblues to do that. Beyondblue can liaise with the insurance industry and, if you want to change the fact that you are discriminated against in the insurance industry, we will put you through to beyondblue or we will put you through to people like Isabell, who are doing wonderful jobs. Our role is to be there for people who are unsure how they are going to get through the next three hours, let alone the next three months and to say, 'Okay, there's no GP on the Eyre Peninsula. We could kill ourselves because there is no GP on the Eyre Peninsula, but what is there? The world might not be perfect now, but what can we do if we get together and ask, "What is there?" Yes, there is an ideal picture of the perfect world, but the world is not perfect and it is never going to be. There are never going to be enough dollars in any budget, but we are intelligent, capable, competent human beings, and we can get together, brainstorm, help each other and share ideas. Particularly, we can do that outside our own worlds, so we can still hold onto being perfect, and say, "Aren't we wonderful, competent, capable career women?"—and men; yes, some people are men, aren't they?—and if we know we can hold that together then we actually do not need to kill ourselves.'

It is things like language, and trying to pull my verbosity together into relevance for my submission, that are incredibly important. For me, the stigma of mental illness has been to seem to be less competent in the workplace. For Miles, the stigma is being seen to be less competent in his career. For 'Moonlight', on the message board—who is one of the most courageous, intelligent, warm, compassionate human beings, who has mental illnesses and has survived some of the most horrific things, as Isabell deals with every day of her life—the stigma of mental illness has been to be seen as a malingerer. What is the stigma of mental illness? We cannot talk about the stigma of mental illness and we have got to stop doing it, because I am not 'a depression sufferer'. When I am a depression sufferer I do not want it to be known that I am a depression sufferer. It sucks: it is an insidious, rotten illness, and I certainly did suffer with it; I am not suffering with it now. I do need to effectively manage a condition. I have a sister with lymphoma who has had bone marrow transplants and et cetera. Thank God I have a condition that is far easier to manage and has no impact, as long as I get enough sleep, on my daily life. I will shut up now and let you have a go.

CHAIR—We are not going to let you do that. Tell us how the internet site works.

Ms Pethick—Importantly, it has three key aspects: information, help and support. You cannot take any of them away, because, as human beings, we need to be able to communicate and we need to be able to communicate from the heart. The communication is going to have elements of help and elements of information. It needs to be checked at all times with an expert in that area—and preferably more than one, because you get conflicting views.

So we provide online information, which is information on the web site, at three levels: there is factual information, then we translate that into English for the average person and then there is information via people's personal experience and opinions of how they have found whatever it might be. There is help, and once again there are three levels. There is access to professional help—we have professional resources on the site. We also have a service where people can email us and we will find options for them. Somebody goes to their GP and the GP says, 'Pray, and God will deliver you.' They come to us and say, 'I'm scared that I'm not going to make it through the night,' and we say, 'Did you talk to your GP?' 'Yes.' 'And how do you feel?' 'I did pray, and God has not delivered me.' 'Okay, let's find you options,' and we just make sure that the next GP they go to see is somebody who does understand depression and will have a little bit more time. Our role is not to pass judgment on the health care industry out there. Beyondblue is going to educate them—beyondblue is going to do all of that.

Apart from that, we do not always know how to be the perfect patient. We go in and say, 'I stubbed my toe,' and come out and say, 'Why didn't they diagnose my depression? They should have—they are the doctor.' Part of what we do at depressioNet is help people to be better patients. Sometimes we lie to our GPs. We tell them that we are only smoking 10 cigarettes a day when in fact we are smoking 20. That is fine—the GP knows about the cigarettes. The GP does not always know how we are feeling, particularly when we get really good at putting masks on.

The other help is very practical help, as in: 'I don't know what to say. It's all right when I'm talking to you here on the internet, but I shut up when I get to my doctor.' 'Hey, why don't you print out what you have just typed or you have just posted on the message board and take it along to your GP and put it on the table—or, even better, go and find somebody else's story off

the site, put it in front of your GP and say, “That’s nothing like me,” but get him in the right ballpark so that you can get started?” It is just about brainstorming, the same way we do about anything else.

The third aspect is support. We provide online communication forums. Five years ago nobody in the mental health industry wanted to have anything to do with depressionNet because of the fear of consumer-to-consumer advice. Then I knew about people with depression; I did not know about some of the mental illnesses that cause severe behavioural issues that are more serious than just the way that ‘normal’ nutty people behave. My attitude was: ‘How do you think the human race has survived? Mothers talk at mothers groups. That is how we know when to go to the doctor. That is how we raise our children—we communicate with each other and we brainstorm and we ask our mums and then we go to the doctor when we need to.’ Why do we need a doctor? That is not the gap. There are doctors out there. The gap for us—we folks having fruitcake and morning tea—is the ability to be able to talk to somebody outside our world in order to get the courage to talk to anybody inside our world.

So it is (a) connecting people to each other and (b) connecting people to the support services that exist out there that might be more relevant. Depression is comorbid with having a pulse, so it is sure as hell comorbid with heart disease, cancer and schizophrenia. There are some things that we do not know. We always make sure that people know where to go to find what it is that they do need.

Senator SCULLION—What sort of response have you had over this time with the various agencies? Did they have a high level of confidence that they should put themselves forward?

Ms Pethick—Absolutely.

Senator SCULLION—Did that come fairly swiftly?

Ms Pethick—I tried to give depressionNet to beyondblue when Ian Hickie was first appointed, and they just did not get it. He just looked at it and said, ‘We are making an internet site.’ He actually did not get the subtlety of what we were doing. It is a powerful thing—it shocked me. I only ever intended to spend four months putting it together. It was going to be my little philanthropic contribution to society. I had been at Telstra for eight years. People in Telstra hit brick walls after 10 years. They do not think they can ever work anywhere else again and they stay there for life. It was not going to happen to me.

I tried to give it to them then. They did not see what it was. They did not see the importance. Six months later I met with Michael Wooldridge and I asked Jeff and Ian—I have enough trouble remembering one name, so please forgive me if I do not use correct titles—to help us out because I had been through my superannuation and all of my savings and I did not know what to do with it. I did not think I was really meant to save the world. They offered to buy it but they were going to close down the online communication forums. It was a matter of ‘I got you girls on that one too’ but I did not look at Ian and giggle. I tried to give it to them, and a couple of months later they were offering to buy it. I thought, ‘Okay, this is interesting.’ So they were going to close down those online communication forums because of legal fears. With hindsight, I can certainly understand that. We are able to do things, from a position where we are all people, that we are not able to do otherwise. You can give someone else a swift kick up the bum if they

know you understand where they are at. If they do not have that confidence then it is natural: 'You don't understand.' That sort of stuff goes, because we do understand—and at times we all need a swift kick up the bum to get up. 'We would not let anybody else talk about you in that way. We will not let you talk about yourself in that way within depressionNet'—we have guidelines as to what is appropriate behaviour and what is not.

Senator SCULLION—What sort of training is there? When recruiting, what is the background of those people who are actually putting things on—and having inputs into—the sites and providing for options and those sorts of issues? What sort of people are they?

Ms Pethick—We stay on the people side of the line. We used to discriminate and not let in anybody with any form of medical or health training. We got over that and decided that they are actually people too and that it is okay as long as they can separate their work life from being human. We stay on that side of the line. What is the criterion? It depends on the particular role. When Keith, our first full-time night person, was found, he was actually in the chat room doing a fabulous job helping other people. I said, 'Keith, you don't want to give up your night job, do you?' and he did and he has been with us now for five years. He was sacked for about four months when I ran out of money in 2001. He had pulled together our first volunteer team at that time.

Senator SCULLION—On another issue: one of the major issues to deal with—and you have heard it right through today—is the stigma that is attached to this and how you educate people. When I was outside I was discussing the background to this with David. Most people in the street will be able to tell you 20 diseases—say, gynaecology, oncology, orthopaedics and paediatrics, and you can go on with heart et cetera—and they will probably talk about post traumatic stress disorder and depression as two others but they would be really struggling to go on with that because it is simply not something that is understood widely in the community at all.

Ms Pethick—Sorry, what is not understood by them?

Senator SCULLION—The wider community do not know much about mental illness, but they know an awful lot about the medical side of things. I think even the names they know—'give me 20 medical illnesses' and they are okay but otherwise they just stumble. I think that is an evidentiary trail to the fact that there is stigmatising simply because there is a lack of knowledge, not because there is any particular intolerance.

Ms Pethick—Absolutely.

Senator SCULLION—You are a fairly innovative sort of individual. How do you think we should be dealing with trying to change the views of people? How do we go about educating the wider community? We can just see what happens and after 20 or 30 years you might be right, but we are thinking otherwise. You have been pretty innovative.

Ms Pethick—I believe that it can be done within three. I know that without absolutely any shadow of doubt. The strategy to do that is: be very careful about communication. A four-page communication can right some of the biggest perpetrators of stigma. It is all just bullet point definitions—what to use in the situation, picking people up just like you do at home when your

daughter is using it—just pick it up and change the word, not in an attacking way but in a fun ‘we’re working on this together’ way.

The second thing is that it has got to come from the people themselves so, instead of fighting stigma, people have to take ownership of it. If you do not know anything about mental illness and if you do not know anything about depression and if you do not know anything about PTSD and I am ashamed of it, what do you learn: more than anything else it is something to be ashamed of. If you say something that is stigma enhancing, my reaction, if I want to change stigma, is not to say, ‘How dare you do that!’ It is to say, ‘Ah! You don’t understand about depression. Tell me this: do you know?’—blah, blah, blah and then enlighten them on that point and say: ‘And is there anything else you’d like to now about it? I can give you my perspective. I can give you some good information sources. If you find anything out there which you would like to come back and ask me about, I would be really happy to help.’

That is the way we change the stigma. Depression is not meant to be a monster. DepressioNet is an environment for people, all of us, to connect. People are the same inside; it does not matter what we do, we are the same inside. DepressioNet provides an environment where people can go outside their real life, 24 hours a day, and always get through and connect. There we overcome the stigma we attach to whatever it is we might have ourselves and then that gives us the courage to go back into our world, because we have been validated as human beings—because we have had those basic needs overcome that stigma. Then we come back up.

My father—I can say this because it is my dad—would say: ‘It’s not like you to feel sorry for yourself. Pull your socks up. Your sister’s got cancer. Get over it.’ It is all right for me—I know my father thinks I am the best thing since sliced bread and that for him depression just does not exist—but for other people it is not all right. So, instead of going away and saying, ‘My father doesn’t understand,’ wrap your arms around him and then go back underground, regardless of his response, and say, ‘I did it!’ and share it with other people. We have seen it happening over the last five years and it is just wonderful. And it is not me, it is not Sarah Cornally, our chair, it is not anybody else; it is all of us. It is ‘mummy moonlight’ and all these people with the most ridiculous user names! I have ‘Leanne’. That is what is happening. We have a three-year strategy coming up that is actually going to provide dNet centres for different sectors, because the one site does not have the capacity once people know about depressionNet.

Senator MOORE—I have been to the call centre at Roma, but I did not have chocolate cake!

Senator FORSHAW—She’s going back!

Senator MOORE—I am going back; I like it! You talked about your employment and how you are operating at a very high level. I am interested in that because Telstra has won awards for its programs to help people with issues who are working in that organisation. When you were working through those things, did you get support from your employer? You said that you had your own internal processes with friends and you told them—

Ms Pethick—I only did that well after I no longer needed support. There was no way I was taking the sick me into my workplace. I was a single mum; we needed my income.

Senator MOORE—One of the things we are looking at in this inquiry is employment for people who identify as having mental health issues. I know that Telstra over the years has won international awards for its process. When you were working through your issues—'journey' is a common term—did you not think about using some of the processes that Telstra was famous for?

Ms Pethick—I would not have gone anywhere near it.

Senator MOORE—Why?

Ms Pethick—Because of the stigma I felt about having depression myself.

Senator MOORE—Did you feel that in your workplace as well, that if you identified—

Ms Pethick—I never even considered it. I was not a neurotic middle-aged female and I sure as hell was not going to claim to be one in my workplace. That was my perception.

Senator MOORE—It worked for you.

Ms Pethick—It worked for me?

Senator MOORE—Yes.

Ms Pethick—No, it did not. Had I not been as ignorant, I would not have got as unwell and would not have been as unwell for as long as I was. It is interesting; I think that the world has changed a little bit. However—

Senator MOORE—It was about seven years ago, you said?

Ms Pethick—Yes. However, one of the issues is that when you have depression you do not think straight. My passion—I have always wanted to do it with depressionNet and hopefully through this three-year strategy we are about to go into I will finally be able to get it happening, because the workplace is my particular passion—is for employee assistance programs. They are great. They are one of many options. What we plan to do is create a dNet work centre and de-stress centre. It does not matter what you call it. We can say: 'We are not qualified to diagnose you. Who cares? Let's get it here before it becomes clinical depression. How are you feeling? Can we do anything about it?' We can work with employees so that we can offer a solution.

One issue is that everybody gets bucket loads of paper. To find a solution, you have to picture the individual and extrapolate from that. I am an individual, sitting at my work desk, with bucket loads of paper. The newspaper comes through and I check the jobs section to make sure that there is nothing I want out there and it then goes into the bin or on to a pile. I have depression—'Shit, I'm feeling bad'—excuse me, that just popped out—'what will I do? There is something somewhere. What bit of paper is it in?' I am not going to ask anybody, am I? 'Where did it go?'

It is not going to be just sitting in front of me. Even if it were, what would it be? I do not know. I did not go to my doctor for depression, just as so many people who come to us do not say that they are feeling depressed; they say, 'I'm losing my mind; I am going crazy.' That is how we feel—'I'm just not me. I have gone and this strange person has moved in who thinks

these strange thoughts and snaps at my husband for nothing.’ People need to know of one place they can go to that is completely safe and anonymous. This was our need, as decided by all of us in the workplace: to go out and find something to meet our need.

People feeling that way now can email telstra@dnet.com.au and say, ‘This is how we are feeling.’ At the other end of that line, somebody would say, ‘Do you know that Telstra offers this, this and this and that you can go and do this, this and this? I don’t work for Telstra. Telstra will not know who you are; you will be identified only as a number.’ I would say, ‘But I still have to give my employee number and I don’t want to do that.’ I would be told, ‘Okay. Look at these other options we can offer you.’ Those options would be sent by email, which then can be printed off. That person might use the information today or in three weeks, but it can be kept handy. It would inform them of the options that Telstra provides. It would list all my options and I can look at them and decide which one is best for me. DepressionNet’s role is to make sure that you make a decision being aware of all possible paths.

Senator MOORE—I might get back to you on that at another time.

Senator FORSHAW—Is your web site accessed by other family members and relatives of people who—

Ms Pethick—Twenty per cent come from that group.

Senator FORSHAW—Does a special part of the site provide advice and information for—

Ms Pethick—Family and friends?

Senator FORSHAW—Yes.

Ms Pethick—Yes. It is very interesting that one of depressionNet’s biggest benefits is that it provides not only the ability to get but also the ability to give. There is nothing more beautiful than to see a frantic mother who does not know what to do with her teenage daughter talking to another teenager who is encouraging and supporting that mother and telling her that her daughter knows what an absolute pain in the butt she is being and that her daughter is actually worried about her as a mother. It is those sorts of things. Family and friends are very much embraced by those within the message board and chat room and enormous empathy is given to them. We know that we are pains in the butt to live with when we have depression; we just cannot do anything about it.

Senator FORSHAW—The stigma—and I am sorry to use that word again—is often very pronounced for family members and in the past may have been even more pronounced. They know there is a problem, but they do not understand it and feel they cannot talk about it.

Ms Pethick—Absolutely.

Senator FORSHAW—However, the person, while they are suffering the episode or the illness, is not focused so much upon that; but later on they may be.

Ms Pethick—Yes.

CHAIR—Thank you very much for your submission and for coming in.

Ms Pethick—Thank you very much. It was lovely to have the opportunity.

CHAIR—I think your evidence has livened us up at this late hour of the day, so thank you for that as well.

Ms Pethick—You are welcome.

[4.23 pm]

CROWTHER, Ms Elizabeth, Chief Executive, Mental Illness Fellowship Victoria

REED, Mr Gerard Michael, Communications Manager, Mental Illness Fellowship Victoria

CHAIR—Welcome. The committee has received your submission, which we have numbered 388. Do you wish to make any amendments or additions to that document at this stage?

Ms Crowther—I have read it and proofread it several times and there are some typos.

CHAIR—Do not worry about typos; we forgive them.

Mr Reed—On page 10, I have said, ‘For a full account, see’—and I have given you nothing. I cannot give you that now either, but I am thinking of a publication about psychosocial rehabilitation, the authors of which are Castle and Copolov. I will have to get the exact title. Is it possible to get that to you at a later date?

CHAIR—Certainly. Whenever you are able to, please do that. We now invite you to make a brief opening statement and then we will go to questions.

Ms Crowther—Thank you. We welcomed very much the opportunity for this inquiry to occur. We believe that there is great opportunity at the federal level to provide leadership within the mental health arena, but unfortunately we do not see it being followed through. We are disappointed that the minister for health has designated responsibility for the particular focus on mental health to a parliamentary secretary. The parliamentary secretary is very able, but nevertheless the minister is not staying within the mandate. The National Mental Health Plan offers great opportunity. I have just visited the UK and have seen what they are doing with their focus on mental health. They have called it a very untrendy name and talked about ‘social exclusion’. Some of the social exclusion that sits with this plan could have been brought more into focus.

We have some local issues around the crisis assessment and treatment teams. I have just come back from Memphis as well, where I looked at police training and intervention at the time of crisis. We have in this state quite an unsafe situation with the crisis assessment and treatment teams and I would be happy to take some questions around that issue.

Under the first mental health plan we were across the nation able to develop some innovative strategies. In this state we deinstitutionalised and did a whole range of things. We did not focus as effectively on how the new structures would talk to one another. There are some real issues—I know that you had VICSERV here earlier today—around the cooperation between services at all levels.

There are some issues within the private sector, particularly in the early part of somebody’s illness. The services they get offered are often office based. When the person becomes ill and needs something outside of the office they very often fall out of that care into the public system,

and the whole development of the relationship reoccurs. There are some fundamental funding issues that make it quite difficult for the private sector to be able to provide some of the strategies that it may well wish to provide which are community based but that bring people back into hospital care.

CHAIR—By ‘private’ do you mean non-government as in the VICSERV organisation?

Ms Crowther—No, I mean private health; I mean private hospitals. Post hospitalisation there are some day programs that have been developed which would be better provided in the places where people live rather than bringing them into congregate care.

In terms of housing, our submission speaks for itself. There are still homeless people in this city every night. There are still elderly people ringing up and saying: ‘I am really frightened. I am 86 years old. My son is 50. What is going to happen when I die?’

In terms of employment, it is absolutely dreadful. If you have a look at the data from the low-psychosis project, it says around 85 per cent of people are unemployed, but if you have a look at the data for those underemployed it is even greater than that. If you have a look at some of the statistics that come out—we have had a look at some during this year—you will find that generic employers will say: ‘A secondary diagnosis—is that a mental illness? Hang on, that’s not the group.’ Of course getting a job for somebody who is unemployed is absolutely important. However, getting a job for somebody who has a mental illness is absolutely crucial, and the outcomes of employment agencies getting jobs for people who have a primary diagnosis of mental illness are dreadful.

Unfortunately, it is not only dreadful in this state and in this country; it is also dreadful internationally. I think that it is compromised further because of the state-federal agreements. With the carve-up in which health is the responsibility of the states and employment the responsibility of the feds, the attitude to treatment here is: ‘We fixed you up. We bandaged you up. Don’t talk to me about work. Go somewhere else for work.’ So I think that the structural issues around that make outcomes for people with mental illness dreadful. To add to that: if you have a mental illness develop in your teens, you are not going to finish your education. If you have not got year 10, year 11 or at least a general certificate of education, you cannot articulate into TAFE and your likelihood of getting a job is absolutely nil.

We have been trying to do some work with this particular group—and we have a whole \$34,000 to do it with—but we are being told that it is a target group but that there is no more money to deal with this group of people. We are into our second cohort this year. Last year we worked with about 20 people and this year we have 18 people. The consistent story is, ‘I partially finished’ or ‘I got into TAFE’ or ‘I tried but I got two months into it and I became unwell. I didn’t attend so I couldn’t get back into it.’ The story for most of the people that we work with now—nearly 40 people—is that they have tried at least four or five times to get those sorts of qualifications. The education systems are not set up to attend to that group. Once again, people say, ‘That’s education; that is not employment,’ and it is not helpful. People actually miss out and fall between the policy areas.

I will briefly raise the issues—I am sure they have already been raised with you—about the health and wellbeing of people with mental illnesses. They are 2½ times more likely to die of

heart disease. Somebody with a mental illness walks into the GP's office and tattooed on the person's lapel is 'I've got schizophrenia' or 'I've got depression' or 'I've got something else.' The likelihood of somebody having their blood pressure taken or their teeth looked at or something else is very low. It does not happen and, as a consequence, the person's life expectancy is absolutely diminished.

In the last submission you heard about the impacts on families and carers. We have a help line. We take about 1,200 calls a year through that. We work with about 8,000 sessions of education—

Mr Reed—Twelve thousand.

Ms Crowther—Is it 12,000 hours now? I beg your pardon. There are 12,000 sessions of education per year with people. What they tell us is, 'I don't know what to ask because I don't know what it is to ask for.' People feel absolutely powerless in the face of a mental illness within their own family. We have evaluated an educational program with 200 people across the country. Surprise, surprise! Anxiety and depression is high. Put in some education, and anxiety and depression reduce considerably. It is not funded. They are the key issues that I wanted to raise with you.

CHAIR—The committee would be interested in your comments about CAT teams. If you would like to expand on your comment that they are unsafe, it is probably a good time to do that.

Ms Crowther—There is a clear perception that, when somebody is in an acute state, they can ring the hospital in the area and a CAT team will come to assess them. That is an expectation that people have. On average, a person may wait for four hours if somebody is going to attend. If the person becomes unwell after seven o'clock at night, they certainly will not get attention that night. Our experience is that when people get CAT teams, they are mostly delighted. So what happens is that the situation escalates and the police go there. The police are just not prepared, because there is an expectation in our community that the CAT teams hold the knowledge and that they will be able to de-escalate within the family.

I have just been involved in a coroner's inquest. A young 23-year-old man had been shot dead by the police. He had an agreement with his parents, before becoming unwell, that should he become unwell they would ring the CAT team. He became very unwell and that was not the case. He had knives and he hurt his father. The location was secured and his mother was terrified her son would be shot. She told the police: 'He is all right. He will be able to talk. Please be careful of him.' The police did everything in their endeavours to get the CAT team. The duty person for the CAT team on the evening of that night, when the police called, did not perceive that they were being asked for assistance. They gave the response: 'Yes, this person has been in this hospital. Yes, this person does have a diagnosis of schizophrenia.' But they did not then go on to say, 'And this person, in fact, has asked before to be killed.' So the police, acting as they believed they should, managed this situation. Something really unfortunate occurred: the young man appeared behind the house and came at a police officer with knives and the consequence was he was shot.

At the coroner's inquest, the CAT team thought that the provision of the information I have just provided to you was enough to give instructions to the police in how to take control of the

situation and the young man. The police do not have effective training in de-escalation; their training is in control, not de-escalation. My submission is that when you have the police ineffectively prepared, and when you have the CAT team not perceiving that they need to attend and, further, saying that they would not attend if their health and safety were in danger, then even if the police could make their health and safety secure we either have to do something about the function of the CAT teams or do something about the education of the police.

CHAIR—Typically, are the CAT teams wilfully not attending or are there mistakes being made?

Ms Crowther—Unfortunately, typically the relatives say to us, ‘If there is any concern about aggression or violence the CAT team will not attend.’ That is the typical conversation that we have with families in all of our educational projects.

Mr Reed—On the other side, if there is not that threat then the person is probably not unwell enough to justify the CAT team going to attend.

CHAIR—Do they ever go out to anyone?

Ms Crowther—Yes, they do. But it is a limited resource. The community believes that they will come at the time. I guess the community has a view that it is an essential service like the police or the ambulance, which in fact it is not. It is an assessment capacity rather than an essential service. If it is not going to be an essential service, we really need to make clear that it is not an essential service and clarify what role they are going to play. That is not happening at the moment.

Senator HUMPHRIES—How is the Mental Illness Fellowship funded in Victoria?

Ms Crowther—We get 80 per cent plus from the state government, we get some from the federal government, we get some from grants and we raise over \$1 million.

Senator HUMPHRIES—From corporate donations or just memberships?

Ms Crowther—Yes, from corporate donations. We run raffles, street stuff and asks. We are part of the Melbourne marathon. So there are a number of strategies. We have been trying to say that mental illness is everybody’s business. We run a ‘five in five’ campaign. You may have seen it on television or in the papers. We say that one in five people have a mental illness but five in five can help. We try to get the issues of mental illness out onto the street and into people’s home because we know about stigma that you can talk as much as you like about it, but until you meet somebody who has a mental illness, until you know that they are okay and have the same wants and desires as you, it is not going to make a whole lot of impact. It is those things that we do.

Senator HUMPHRIES—You spoke about the need for more employment opportunities. I put it to you that one of the main problems with mentally ill people not being employed is the rigidity of our employment system. An employer might decide that they were going to make a position available for mentally ill people, but as a job share with, say, three people, so that when the mentally ill person was well enough they could come and fill the position; when they were not one of the other three would—a flexible arrangement like that. The chances are that it would

not fit with any award that exists anywhere in Australia. Do you see the capacity to register special employment arrangements for mentally ill people outside existing award systems, for example, as a way of being able to create the sorts of employment opportunities that you have described as being vital?

Ms Crowther—I do not think one answer fits all. The fellowship run a program with Telstra where we own the job and we put people in there to do the work, so we act like a broker. Those people work in the mail room at Telstra, for which Telstra won an award the year before last. That works. It has limitations, because the person does not feel that they own the job, but it also has positives. I think there are a lot of options. We also run a small business called the Flat Bottle Company and we employ people who do not have a mental illness and people who do have a mental illness.

I think that even within the award situation there are opportunities, but the issue is how we work with employers to deal with those opportunities. In our one in five campaign we interviewed 200 people off the street. An external agency did it for us. We found that, when it really comes down to it, people do not know what mental illness is. If you do not know what something is, you do not know what to do. They were still frightened because they did not quite know what to do. When you put somebody on a job and they have diabetes, for example, you know that they are not going to fall over or do something like that, but you do not quite know whether that is the same with mental illness. It is a matter of doing some strategic work with employers to run some pilot projects, but in real ways, not just doing the education. It is about having people working there. You can talk and talk as much as you like but you have to develop the demonstration projects. Does that answer your question?

Senator HUMPHRIES—It does. I assume, though, that in these cases you are looking for employers who are either big enough or generous enough to make these special arrangements which almost certainly are more costly than they would be for an employee who is not mentally ill. I am suggesting that you might actually attract more employers into this arrangement if you gave them something in exchange—that is, a more flexible working arrangement.

Ms Crowther—The NHS in the UK have done some work on this and they have looked at that cost issue. They discovered that people with a mental illness really want to work. I am generalising here, because you can have somebody with mental illness who is a dud, as you can have somebody who does not have a mental illness who is a dud. But, looking at the figures, they found that the reliability of somebody who had a mental illness was greater, and hence if you employed somebody with a mental illness you did not have the greater recruitment costs that you would have with your normal turnover.

Senator HUMPHRIES—Most employers might not appreciate that, though, unless they were shown those figures.

Ms Crowther—Sure.

Senator HUMPHRIES—On page 2 of your submission you say:

The agreed model of mental health treatment includes biological ... rehabilitation components ...

What are biological rehabilitation components? It is the second dot point on page 2.

Mr Reed—It is basically talking about medications, medical intervention, and receiving psychological and social rehab.

Ms Crowther—That is one of the things that is opening doors for people. There is a new medication—I will not name it—that has just come onto the market, and for some people that has been fantastic. There was a new medication before that, and for some people that was fantastic. So, for somebody who has not been able to do a whole lot of things, a door has opened and they are feeling better. But they do not have a job history, stable employment or stable education and that poses considerable risk. It is very often a time when people feel so wretched and miserable that they suicide.

Senator FORSHAW—I want to put forward an observation following on from Senator Humphries's questions and your comments about employment. One of the impacts of the whole changing nature of the work force is that there are a lot fewer large employers. Less public sector employment has been a problem in being able to offer employment to people. Government departments, institutions, authorities and whatever are better able to cope with employees taking time off for leave, sick leave and so on. One of the issues that has been brought to our attention is the role of GPs, training et cetera. You might take the opportunity now, if there is something you want to say, to comment on that whole area of GP interaction with organisations like yours. How do you rate the programs that are currently in operation to improve training and the service that GPs are able to provide, or should be able to provide, to mentally ill people.

Ms Crowther—They are very well intentioned.

Senator FORSHAW—The groups, the programs or both?

Ms Crowther—The programs. GPs have a real difficulty because, if they have a large psychiatric practice, some of the funding they get for that practice is limited. GPs have said to me: 'Liz, if I've got somebody who is unwell in my rooms and I can't get a CAT team in there, what do I do? Take them home with me?' There are some fundamental issues for GPs and the support, such as practice nurses. There may be some processes around that that may help in development.

The UK are beginning to experiment with a process where GPs write employment prescriptions and education prescriptions. Their funding arrangements are quite different from ours, so we would have to explore what that meant here. Basically, if somebody comes into their practice who does not have employment, and that is critical to their health, the GPs are able to say to that person, 'I will write you this prescription that will connect you with this particular agency who will work with you to get a job.' I do not know about the funding part. But they are beginning to experiment with that. Our difficulty is that GPs do not see employment as part of health. We have this really segmented stuff. Health is our business, education is the education department's business and employment is the employment department's and employer's business—it is not necessarily a health issue. I cannot say, because I have not monitored it or asked questions, but I do not know that many GPs would know what the local employment service was.

Senator FORSHAW—Back on the health side of it, we are told by various groups, the divisions themselves, that we are seeing improvements in the level of training and understanding of GPs, despite all the pressures that are on them, and that they are endeavouring to pull their weight. Is that your experience?

Ms Crowther—Very often GPs see the mental illness; they do not necessarily see the whole person, or they very often do not diagnose the mental illness if the diagnosis is not made.

Mr Reed—Anecdotally, through the families we work with, GPs get pretty good press—certainly better press than certain psychiatrists.

Senator FORSHAW—We have picked that up.

Mr Reed—Yes, I am sure you have. GPs can be the family doctor, so there is already a relationship with the family, whereas psychiatry comes out of left field and therefore there is no relationship with the family and the family is often excluded. The horror stories we hear are far more often about psychiatrists than about GPs. From families that I have worked with, GPs generally get a pretty good run. If anything, I would say it is patchy: some GPs have an interest in mental health and therefore do some work on it, and others just do not see the sense.

Senator FORSHAW—Do you have any interaction with the Victorian divisions of GPs?

Ms Crowther—Yes, some.

Senator FORSHAW—Or with the AMA, in focusing on this area?

Ms Crowther—Yes, we do, via some of the divisions. But there are very many divisions. That is what the difficulty is. We were working with one division, and they were terrific. But there are not very many of us, and going to regular meetings and stuff is really very onerous. I am a bit noncommittal about it because there are so many divisions.

Senator FORSHAW—It has been said to me—and I think we have all heard it—that the pharmaceutical companies have far greater influence and take on more of an educative role. That of course raises issues about motivation and so on.

Ms Crowther—Yes. We do some fact sheets and stuff, which people find useful. But if you go into a GP surgery you will not see those around, because we cannot get there. The GPs get deluged with a whole lot of stuff. We can send them there, but they will get turfed out with the other stuff that goes in there.

Senator MOORE—I have two things, one following directly from that. Your submission mentions GP training and the better outcomes stuff. I note that that is supposed to be focused. GPs who do their six hours are supposed to be given a list of all the resource people. Have more GPs come to you or sought you out after they have done their training?

Mr Reed—I would not know. Probably about 10 per cent of the calls to our help line are from professionals, which include some GPs.

Senator MOORE—So it could be them.

Mr Reed—That would have increased over the last two years. But we have never asked the question.

Senator MOORE—And you have not been involved in the six hours training as consultants?

Mr Reed—No.

Senator MOORE—My other question is much more general. In your submission you have highlighted priority areas. What do you expect to come out of this inquiry? What do you hope this inquiry will achieve?

Ms Crowther—I would hope that it would give some focus on the National Mental Health Plan. That is what I would really hope for—and that it could be made more real. I am sorry; I should not be saying that.

Senator MOORE—Your submission says that.

Ms Crowther—But I did not quite say it in those words. It needs to get a bit of teeth. That is really what I would hope. I would really like to see some high-level intersectoral work. I am not necessarily saying that you have to put all new dollars into something. What I am saying is that, if you look at some cross-sectoral stuff, you can begin to develop some pilots and, over time, you can begin to rebadge money. I would hope that that can be achieved.

I think we have a national crisis around employment and that, somehow, someone in the power levels needs to work out that we can move it from health and housing and pensions. If you add it all up together, that is what the real cost is. It does not just sit in one area so that it is really costly. The other thing is that we have to do something, in very practical ways, around mental health literacy, because that underpins whether somebody is going to get a job, stay in education and be socially visible in our community.

Mr Reed—I think we run very much on a deterioration model. We wait for people to get sicker before we often them treatment. As soon as they have passed a certain point of sickness, we basically say, ‘You’re off the agenda until you’re unwell enough to come back in.’ That means we throw a lot of money at the clinical end rather than at recovery pathways that make sure people do not end up back in hospital. And it is cost prohibitive to have people in hospital all the time. If any shift is to happen, we need to spend the little money we have more effectively, and it is definitely in that end. That would be my hope out of this.

CHAIR—Thank you very much. Thanks for your submission and for appearing—and for being the last today, which is not an easy call.

Committee adjourned at 5.00 pm