



National Network of Private Psychiatric Sector
Consumers and their Carers

SUBSEQUENT SUBMISSION TO
HOUSE OF REPRESENTATIVES STANDING
COMMITTEE ON HEALTH AND AGEING,
INQUIRY INTO HEALTH FUNDING

NATIONAL NETWORK SECRETARIAT

Box 6090 PO
KINGSTON ACT 2604
Telephone: 02 6270 5438
Fax: 02 6273 5337
Email: ptaylor@spgpps.com.au

1 SUMMARY

A chance very brief meeting between the undersigned and The Hon. Mr Steve Georganas MP, following our ~~appearenace~~ appearance at the House of Representatives Standing Committee on Health and Ageing's Inquiry into Health Funding in Canberra in September 2005, has prompted this subsequent submission.

As previously advised, the *National Network of Private Psychiatric Sector Consumers and Carers* (hereafter National Network) represents Australians who have private health insurance cover and who receive their treatment and care from private sector settings for their *mental illnesses or disorders*. As our title implies, the National Network is the authoritative voice for consumers and carers regarding the policies and practices of funders and providers in private mental health settings. We therefore highlight within this subsequent submission, some unique difficulties regarding mental health.

This subsequent Submission should be read in conjunction with our original Submission in which we outlined in some detail, the problems associated with the funding of mental health services within the private health sector.

In this Submission, we invite you to 'get inside the head' of someone with mental illness, and the difficulties they encountered in trying to understand financial and other matters during an acute phase of their mental illness. This Submission represents the lived experiences of two private sector consumers, expressed in two narrative stories. One addresses the issues faced by someone during hospitalisation. The other highlights issues related to continuity of care.

We hope these stories have a positive impact on the Standing Committee's deliberations.

Please note, that in this subsequent submission, the term *Hospital* refers to private hospitals with psychiatric beds and the term *Health Funds* refers to private health insurance funds that pay benefits for psychiatric care.

Ms Janne McMahon
Chair National Network
Ph: 02 6270 5438
Fax: 02 273 5337
Em: ptaylor@spgpps.com.au

2. OUR FIRST STORY

A woman in her mid fifties has written this story. This mental health consumer was formerly a teacher in History and English and more recently, a senior member of State Government. She was forced into early retirement, signalling the loss of career, due to mental illness. *Her mental illness is chronic and it should be noted that the all costs associated with her hospitalisation as both an inpatient and Day Only patient were met by her Health Fund over a considerable period of time. Many mental illnesses are chronic, complex and represent a high cost care to health funds.*

You ask me what is wrong. You know me well enough by now to sense the unwellness in me. But still I find it so hard to explain – to explain this ache, this perpetual ache inside me. You want so much to help but where - how – do you begin you ask. I cannot answer for I am bound by waking nightmares that scourge the mind and inhabit my very being. Mood swings fill my mind. Grappling the next high - the next outburst of mania with its wonderment and exultation; its fantasy and surrealism; its devastating consequences. The after-burn of mania: depression, with its fears and desperate thoughts, a mind overcome by dreadful sensations and feelings of hopelessness. Thus begins the downward spiral, into the black-liquid depths of despair where the soul is lost and the mind is numbed, where the body is delivered up to exhaustion and fatigue.

You, my carer, want to be part of my journey – to share the journey. You are my rock; you are my steadfastness. Sometimes, though, it can be so difficult to ask for help – to even see that I need help for my mind can be a whirlwind of lost thoughts and jumbled notions. Sometimes it is a complete blank. And then I cannot move; physically I feel nothing but fatigue. My mind slips into numbness and all pervading blackness. My psychiatrist is also part of my journey - my sign post – suggesting directions that I might explore; together, over time we explore options for living, for recovery. Slowly, slowly. Thus begins the journey... it is always a beginning...a never ending beginning.

Box 1: Legislative barriers to early intervention

Current legislation precludes health funds from funding preventative or early intervention programs in the private hospital-based setting.

(Note: some health funds do fund early intervention and preventative programs in out of hospital settings however)

For three months, I slide ever deeper into depression. “I am in a deep black hole – a dark abyss. How long I have been there I do not know – days, weeks, months – I do not know. I feel weak, without energy, completely fatigued. I have only one thought which will not leave my brain: death. People are talking at me, around me but I do not comprehend.

I visit my psychiatrist in her rooms. We talk. About my depression, about my bleak thoughts, about my suicidal feelings. She asks me whether I would act upon my thoughts. I hesitate and do not answer. She repeats the question. I hesitate again. She repeats the question a third time – this time with the proviso that should I fail to answer she will take steps to have me admitted to hospital.

My body shakes, I cannot stop my hands from trembling. In another life I spill the coffee and feel the embarrassment. I wish I were dead. But how? Outwardly I smile. Inwardly I'm torn asunder; my mind is on fire; sleep; I want sleep and an end to the pain.

I do not answer my doctor. She picks up the telephone and I am done for.

I am being admitted – that much I know. I sit next to my bags and wait to be admitted. And wait. My husband is with me – thank God – because I could not have done it without him. All I want to do is escape – run away from the Clinic; talk myself into thinking there is nothing wrong with me, but the trembling hands and throbbing temples give the game away. I'm facing ECT during this admission this much they have told me and I have agreed to it. ECT: I've hit rock bottom with my depression this time; I can't escape these all pervading thoughts of death and suicide; everything is so bleak.

I cannot tie up my shoe laces. I am 53 and cannot tie up my laces. The tears stream down my cheeks. The nurse suggests I wear a pair of slippers.

Box 2: Informed Financial Consent

While feeling this way, the consumer is expected to know:

- whether they are required to serve any waiting period with their Health Fund cover, if it has been taken out over the previous 12 months.
- whether their level of chosen cover has any **front end deductibles**, such as **excesses** that have to be paid by the consumer. If so, it is the consumer's responsibility to know how much they will be required to pay.

(Note: Hospitals are expected to check a person's health fund eligibility prior to admission. A new system called Eclipse run by Medicare Australia, will allow this check to be done on the spot by the hospital)

If the consumer cannot answer these questions and it is after hours, then they will be required to be admitted overnight, until their insurable status is confirmed with their Health Fund on the next business day.

The consumer must ascertain whether their Health Fund and Hospital have a contract between them that will cover the full cost of the hospitalisation. (The hospital can confirm this.) If the hospital does not, then the Health Fund is obligated to pay the *Basic Default Benefit*. This means that the consumer will have to pay approximately \$200, **or more**, per day from their own pocket for the entire length of their stay (see the discussion of disputes and out-of-pocket expenses in the National Network's original Submission).

The Hospital may only attract 2nd Tier Benefits, which will be approximately \$150 to \$200 per day **less** than what the consumer is covered for. This means the consumer will have to pay approximately \$150 to \$250 out of their own pocket for the entire length of their stay. (see the discussion of disputes in the National Network's original Submission)

At this very moment, the consumer must ascertain the costs of the hospitalisation, understand the possible consequences, and make a decision whether to continue with the hospitalisation. (eclipse will assist with this information)

I am not able to comprehend them – My husband is providing most of the answers – what is preventing me from the most basic of communications? My mind is in a whirl and my mood is beginning to change. I am beginning to feel angry and irritated; so many questions and we seem to have been sitting here waiting for admission for ages. I am tired and all I want to do is to lie down and try to sleep; I snap and my husband has to calm me down – I am offered a tour of the Clinic but I decline. I am feeling deeply distressed just going through the admission process – so much to discuss and so much to remember. As it turns out I fail to remember anything of my admission in the days ahead and need to have all the rules and protocols explained to me again when I am a little more settled. I feel desperate and isolated; too much activity around me – about me – I am a statistic; a Medicare number, a health fund reference. I am frightened.

Box 3: Hospital Run Programs

Hospital run programs for inpatient services are funded by **Health Funds** and are included in the amount paid, per day, for the admission period. It is the **Hospital's** responsibility to structure them, and to provide positive outcomes for her and others.

It's the routine that gets to you. The routine of waking, eating, medication, sleeping. The boredom of the long hours in between therapy. The initial fears give way to other anxieties: of wondering how long one will spend confined in the Clinic; of when one will be allowed leave to walk down to the beckoning sea; the anxiety of missing the basic freedoms we just take for granted on the outside. The boredom is tangible – at times I think I'll take up smoking just to pass the time away – the smokers seem to find enjoyment in each others company. The boredom is cancerous: it eats at your very soul and leaves one a pitiful, whinging, anxiety-prone wreck. Therapy programs provide a welcome relief from the empty hours; a chance to focus on positive energies and outcomes. I enjoy the interaction of the groups – there is so much spontaneity and openness. I value the contact as it feeds and nurtures my inner self, helping me to grow in self-esteem and self-confidence.

I feel nervous and anxious about discharge. I have been in the Clinic three and a half months – it seems a lifetime and I don't think I can cope on the outside yet. What will it take to make me able to cope? I have a wonderful husband and two caring daughters and a fantastic psychiatrist. That's a solid start. But I am so nervous in myself: I lack the confidence in myself. What will I be like, how will I cope when I am at home by myself?

Box 4: Inpatient Programs and Discharge

At this point the consumer would have to understand the following.

- Does the Hospital run programs, and does their Health Fund cover the costs of those programs.
- Are the programs provided within the Hospital, recovery focussed?
- Are there sufficient programs available to meet the consumer's needs?
- Is there enough variety in the programs to stimulate positive outcomes?
- Are the programs provided in the right setting at the right time?

Many private hospitals run programs on discharge processes and how to access self-help programs run within the Community by non-government organisations. **Discharge** from Hospital, however, can be an overwhelming challenge and consumers are often anxious about whether they will be able to access any services run by the Hospital after its doors have closed behind them. What is needed to support consumers, how this can be provided, and whether Health Funds have the capacity, within **legislative requirements**, to pay for these services, are all issues that are critical to a consumer's recovery after they leave the hospital setting.

I am reassured there will be a program in place to support me once I have left the Clinic – a Day Program that I can attend twice a week. That's fine, but what about the other days? I fear being by myself – I am frightened that the voices I used to hear – the voices that put me into the Clinic to begin with – will reappear. I am frightened I might turn suicidal again. Suddenly I feel that all the achievements of the past three months have dissipated, that I have gone back in time to when I first arrived at the Clinic. I burst into tears. I am told that my reaction to leaving is quite “normal” Okay, I accept that, as long as I know there will be support if I need it I'm willing to give it a try. I suppose that's all I can do.

I need people to understand that I live with mental illness rather than suffer with mental illness. The distinction is important as the former gives me control while the latter makes me a victim. I am not a victim of mental illness; I have a mental illness, but it does not have to limit the creative living of my life.

For myself I wish that I could stay as healthy as I am now – with the self confidence and the sense of freedom and fulfilment that I currently possess. I continue to need the support of family and friends as well as health professionals. My psychiatrist will continue to play an important role in managing my mental wellbeing as I require an ongoing medication regime and therapy. I cannot do this alone – that much I recognise. I am offered support via the Day Programs – a much needed lifeline as I still feel very emotionally fragile since leaving the Clinic. I go twice a week for Day Programs – life savers. The other days I sit at home, scared and anxious. I wonder when this will ever come to an end – when will I ever feel whole again? The Day Programs give me the chance to interact with likeminded patients – a chance to share our fears and hopes, a chance to release some of the pent up feelings of anxiety and frustration. I feel stronger for the experience; I feel liberated for the sharing.

Box 5: Outpatient Services

This is often the most crucial facet of private psychiatric services. Programs of this type are provided on a day patient, or outpatient basis. They are usually time limited, according to the program outline. One major Health Fund does not recognise half-day status. Issues of **exclusions, limitations, co-payments, and legislative barriers** have a direct impact on the consumer here.

As for patient education it has been very much a case of what I could find out, not what was delivered to me. Whilst in the Clinic I wanted to know more about impacts and side effects of my medications. I also wanted to understand the impact of ECT. It might seem simple that I could ask these questions, the fact of the matter is that I was not well enough at the time. I was not in a position to assert my basic rights for information.

Box 6: Required Information

At this point, some of the issues the consumer would have to understand are set out below.

- Does the hospital have an Australian Government Approved Outreach Program AND does the consumer's Health Fund offer cover for the Program? [\(Eclipse will provide this information\)](#) **If yes**, then this Program is offered to support the consumer in their home. A mental health professional from the hospital may call once or twice a week or on some other schedule. **If no**, then the consumer cannot obtain direct support within the community setting, and is required to attend the hospital, as a Day Patient, for Programs run by the facility.
- Does the consumer's Health Fund cover the full cost of the Day Patient Programs the consumer wishes to access at this Hospital? [\(Eclipse will provide this information\)](#)
- Does this Hospital and the consumer's Health Fund have a dispute as to the amount that will be paid to reimburse the consumer for the costs of accessing the Day Patient Programs? **If yes**, then she will be required to pay a co-payment of anything up to \$50.00 per session.
- Is the consumer accessing a set program of say one day a week for eight weeks? If so, then the consumer may be required to pay \$400.00 in co-payments.
- Does the consumer's Health Fund have a limit on the number of days they can access Day Patient Programs per annum? [\(Eclipse will provide this information\)](#)
- Does the consumer's Health Fund require the consumer to attend for a full day (5 hours) or can they access a Half-Day Program? [\(Eclipse\)](#)
- Are the programs provided by the Hospital recovery focussed and is there sufficient variety in the programs provided to offer positive outcomes?
- Are the programs run for a sufficient length of time to sustain gains?

- Are the programs the most appropriate service, delivered in the most appropriate setting at the most appropriate time?

Current Legislation precludes Health Funds paying for programs, which are preventative care focussed. ([Funds can pay for preventative programs under ancillary cover if the wish to](#)) It also precludes Health Funds paying for programs, which are not a direct **substitutes for inpatient care**

Carers are often neglected when it comes to education and the provision of information. Their needs as carers are often overlooked. They need to be provided with information on the nature of the mental illness, treatment regimes, medications and programs. Too often the carer is marginalised when they should be seen as part of the treatment strategy.

Box 7: Carer Needs

Here the consumer is expressing concerns over whether:

- there are programs which her husband, as her carer, can access for his needs.
- he has been offered information and education about her mental illness to cope with a crisis or ongoing support.
- legislation precludes his health fund from paying the hospital the financial cover for this type of service and, if the hospital does provide such services, then what will be the cost to him.

Current legislative barriers preclude the payment of information/support services to carers.

I have moved on from the Clinic and Day Programs. I have reached a point of stability and comfort in my life, which is fulfilling. I have occasional bouts of depression and mania but these have been managed with medication and therapy.

I have found some part-time employment and I also do some volunteer work in the mental health sector. I know I need to keep busy, to keep my mind active – without overdoing it. I haven't been hospitalised since 2001 – maybe because that particular time in hospital was so long that I vowed it would be the last time. Now, I try to live each day as it arrives – strong in the knowledge that I am a survivor.”

Box 8: Community Care

As detailed in, and attached to, our original Submission to the House of Representatives Committee attention is again drawn to the **Guidelines for Determining Benefits for Health Insurance Purposes for Private Patient Hospital-based Mental Health Care**.

These Guidelines were developed in consultation with Australian Government Health Funds, Hospitals, and the Royal Australian and New Zealand College of Psychiatrists (RANZCP). They were intended to assist Health Funds when approving psychiatric care programs for the purposes of health insurance benefits. The Australian Government distributed the Guidelines under cover of HBF Circular No 100, dated 8 September 1987.

In 2000, a Working Party comprising representatives of RANZCP, Health Funds, Hospitals and Consumers, revised the Guidelines, in consultation with the then Commonwealth Department of Health and Aged Care, Private Health Industry Branch. The revised Guidelines were endorsed by the Strategic Planning Group for Private Psychiatric Services on 23 February 2001 and distributed under cover of the CDHAC HBP Circular No. 694 PH 433, 5 March, 2001.

3. OUR SECOND STORY

The following narrative expresses a consumer's needs according to a continuum of care. As such, it represents what would be considered a true continuum of care. Please note, that a number of the services outlined below, cannot be funded because of legislative requirements. The continuum of care include the following.

- Early intervention
- Crisis assessment
- Domiciliary/community care
- Outpatient services
- Day, half-day, partial-day and evening services
- Hospital programs
- Admitted overnight services, where necessary
- Maintenance and supportive care
- Patient and carer education
- Preventative care
- Discharge planning

Current legislation prevents health funds from funding any services designed to intervene, or prevent hospitalisation. Funded services must be on the basis of an 'admitted patient' status, and can not be an 'add on' service.

Our Second Story, has been written, in dot point format, by a man aged 55, who was a senior master in teaching, in a public secondary college. He trained and taught for 34 years. He lived in a rural area and needed to relocate to a metropolitan area for his mental health care. He has also been forced into early retirement, and the loss of his career, because of his mental illness. *His mental illness is chronic and it should be noted that the all costs associated with his hospitalisation as both an inpatient and Day Only patient were met by his Health Fund over a considerable period of time. As mentioned in Our First Story, many mental illnesses are chronic, complex and represent a high cost care to health funds.*

- *1997-1998 Becoming suddenly and unexpectedly depressed, bursting into tears in private for no apparent reason; I seek refuge in work and alcohol.*
- *Discuss my problems with no one since I feel that I'm going mad. Now working almost 16 hours a day and 6 days a week. Deliberately make myself more isolated, professionally and socially. Feel like being on a merry-go-round with many sleepless nights, horrific nightmares and totally negative feelings, all exacerbated by the gradual but inexorable break down of my marriage.*
- *Finally, overcoming the bitter shame I feel from suspecting that I may have some serious form of mental illness, I make a confidential appointment to see my GP. He sees me for no more than 10 minutes, tells me I'm depressed and prescribes anti-depressants. My situation does not improve: I desperately need help.*
- *I return to my GP who merely changes my medication. No referral to a psychiatrist or psychologist, despite the fact that I have private health insurance.*

- *Situation becomes so serious that I can no longer cope. Become suicidal, and plan my suicide in some detail. Drive into a concrete pole, completely destroying my car but not myself.*

Box 9: Crises Assessment

This cannot be done at a private hospital with psychiatric beds. Admissions to inpatient services must be via the private psychiatrist. Medicare of course, covers 75% of the costs of the psychiatrist's consultation fees, and the Health Fund reimburses the additional 25% of the fee.

- *Admitted to the psychiatric ward of a public hospital. Extremely depressed, confused and afraid. No formal programmes, no psychotherapy, and I can see the doctor for only twenty minutes a week. Commence ECT, but conditions are deplorable. By sheer chance, a nurse discovers that I have private health insurance, and mentions the existence of a private psychiatric hospital in the capital.*
- *I discharge myself from hospital, hire a taxi to the local airport and catch a small plane to the private hospital. I am very desperate and feel very alone. I finally persuade the resident psychiatrist to admit me. Even now I have second thoughts, expecting all the patients to be insane and even homicidal. Yet, I am also very relieved to discover that I have an illness that can be treated.*

Box 10: Admitted overnight services – Hospital Programs

It is in this area that sometimes difficulties are incurred. Co-payments, disputes, limitations on what health funds will fund, and how much they will fund. It is also a reflection of the status of the hospital. Does the hospital have a contract with the particular health fund? Is this information known to the consumer? [\(see Eclipse as above\)](#)

It is expected that private hospitals will provide In-patient programs, which are recovery focussed, and offer positive outcomes. They should be of a high standard. The costs of these programs are contained within the payment the health funds pay for the per day benefit.

- *After a physical check and basic orientation, I retire to my room. I know no one and do not know what to expect in terms of my treatment. I feel afraid because I cannot lock the door to my room, and I have not yet met the other patients.*
- *Later some of my fears are allayed when I meet the other patients and realise that we have much in common. But I am still worried and confused because there has been no mention of a treatment plan except that I shall continue to have ECT.*
- *My situation slowly improves as I participate in the hospital programmes, learn how to relax, get to know my psychiatrist and the nursing staff, and socialise with the other patients.*
- *Nevertheless, I have several major misgivings. I am not alerted to the possible side-effects of my new medication, I have no visitors because of the distance factor, I cannot gain access to any of the hospital's psychologists (and was not able to during my three subsequent admissions), there is no apparent treatment plan, I have too much free time on my hands, and there is never any mention of my discharge.*

- *I am admitted for eight weeks on the first occasion, and I am strongly motivated to attend all the hospital's programmes because of the strong emphasis on preventative care.*
- *But I am extremely anxious because I realise that there can be no post-discharge follow-up since I live 350 kilometres from the hospital. In fact, there has been no attempt by my doctor or the nurses to plan my discharge.*

See Box 4: Discharge and Inpatient Programs above

- *I am suddenly and unexpectedly told that I am to be discharged. I am very anxious because I have become accustomed to the hospital's institutional way of life and protective environment, and I know that I shall be literally on my own when I leave. I leave without any resources to assist me if there relapses in the future, other than my GP who has no special expertise in mental health.*
- *I leave already knowing that I cannot return to work and that I cannot face my friends and colleagues because of the stigma associated with mental illness in my town.*

Box 11: Maintenance and supportive care, and outpatient services

It is in these areas that probably most of the difficulties occur. Again, co-payments, disputes, limitations on what health funds will fund, and how much they will fund, and if they can fund. Legislative barriers have serious implications as to what health funds can pay for. Maintenance, supportive care, and preventative care, are all affected by legislation. Good quality programmes can sometimes be scuttled because of legislation.

- *Other than visits to my GP, and very occasional visits to a public psychologists and a part-time private psychiatrist, there is no meaningful supportive care and no outpatient services. I spend almost every day at home by myself. My depression worsens and is compounded by extreme loneliness, misery and self-pity. Moreover, I am becoming increasingly resentful because I cannot access the assistance that I require. Hence, there are long bouts of sleeplessness, irrational behaviour and almost total absence of anger management.*
- *Needless to say, there are three more serious relapses and three more admissions to the private hospital.*

Box 12: Day-patient services

Health Funds pay a great deal of monies toward psychiatric care. Mental illness is most often chronic, whole of life and is a drain on their resources. Payments for chronic illness can escalate. It is easy to see from this example, that a privately insured consumer accessing day-patient services, twice a week for a full year, can amount to a great deal of costs for Health Funds.

The Health Fund in this example **covered all costs** of hospital programs.

- *After the fourth admission I make the very desperate decision to end my marriage, move to be near the private hospital and my psychiatrist, and 'force' the hospital to provide maintenance and supportive care by joining the day-patient programme.*
- *I am a day-patient for one year, attending twice a week. It is the best decision that I have ever made concerning my mental health. It enables me to make the transition between an institutional environment and living by myself. It allows me to learn and*

implement relapse-prevention skills in a completely realistic manner, and it means that I can gain assistance immediately if required.

- *I have not had a serious relapse requiring admission during the last five years. I still see my psychiatrist and have frequent contacts with the hospital in my role as a consumer representative.*

Box 13: Patient education and community care

You can see from this example, that this hospital did not have an Approved Outreach Service. There are only 12 of 46 private hospitals with psychiatric beds nationally, that provide this service, paid for by Health Funds. Approved Outreach Services are a known way of keeping people out of hospital, or lessening their length of stay, if hospitalised. They support people in the community.

- *I have often felt that the hospital could have helped me a little more in two ways after I completed the day-patient programme. First, it could have made me aware of the community services available to help people with a mental illness. I have used some of these services, but only after stumbling on them almost by accident.*
- *Secondly, since I live by myself, I think the hospital could have asked its community nurse to check on my progress at least once in five years.*
- *Thankfully, now that I am a consumer representative, I can make the hospital aware of my concerns, and at the same time appreciate the financial restraints on its capacity to deliver more comprehensive and innovative service delivery.*