

Senator Claire Moore
Chair
Senate Community Affairs Legislation Committee
Parliament House
Canberra ACT 2600
By email: community.affairs.sen@aph.gov.au

Dear Senator Moore,

***RE: Social Security and Other Legislation Amendment Bill 2011
Schedule 3 (Disability Support Pension Impairment Tables)***

I hope this submission is not too late to be considered by the Committee. You will notice as you read my submission that I disclose a deal of very personal information. I request that my submission be published with my name withheld.

I receive the DSP, and have done since 1997.

I would like to address the Mental Illness (MI) aspect of the Impairment Tables (IT).

I have had some difficulty putting together a submission for this important inquiry. The problem has been my illness, I have Bipolar Disorder (BP) and I can never be sure when disabling symptoms will recur. The Secretary granted me an extension until Monday 22/08/11 but unfortunately circumstances intervened and I've not been up to working on the submission in a timely fashion. I also have some loss of neurological executive function, which impacts on processing ability, concentration and short term memory. This neurological damage is the result of oxygen deprivation to the brain caused by my near fatal suicide attempt in 2008. It was my 4th attempt in the last 25 years. Three of which have placed me in a coma. Consequently I have rambled a bit in this submission, it is not as tight as I would like, but hopefully amongst its paragraphs some useful information may be found.

Before I proceed any further I would like to refer the Committee to the Investigative Report by the Commonwealth Ombudsman "falling through the cracks" which was completed last year. <http://www.ombudsman.gov.au/reports/investigation/a-to-z> Report 13/ September 2010 – download link. This report considered a range of issues that involved Centrelink, DEEWR and FaHCSIA and these Departments' interactions with the mentally ill. It also referred to the role of JCA's and the Impairment Tables (IT). It is an eye opening look at the processes from a body with no policy agenda to pursue.

I must also express my shock in finding that the IT are not to be included in the Social Security Legislation. Surely the fact that we have had an Advisory Committee, an Actuarial study as well as this Inquiry and the public Information Workshops to follow later in the year, to effect change to the existing IT, is evidence that the IT are too important, and require significant consideration and scrutiny from a large number of stakeholders, to allow them to be amended "at the whim" of the Minister. There may be a change in the composition of the government and a new minister may have much "harsher attitudes" towards DSP policy and catastrophic changes could be made without public comment or involvement. This is not the way I expect an Australian Government of conscience to make a change in the law. We do not move the goal posts without notice and discussion in this country.

As stated earlier, I was granted the DSP, in 1997. That was because of the chronic nature of the Bipolar Disorder (BP) I have suffered since my late teens. I was not correctly diagnosed however, until I was 30. This is not unusual, a large number of people - there is research on the number, but I think it's about 40% - are misdiagnosed, you will be familiar with these studies from your work on the Mental Health Inquiry. Misdiagnosis is one of the first problems a person faces when they apply for the DSP. It is a specific requirement that a diagnosis be made:

Impairment Table 5 should only be used where the person has a diagnosed psychiatric disorder resulting in functional impairment (this includes recurring episodes of psychiatric impairment).

This diagnosis must be made by an appropriately qualified medical practitioner, with supporting evidence from a psychiatrist or clinical psychologist.

While it is understandable that the DSP be granted only to those with a genuine condition, the professionals do get it wrong. If somebody who has been on sickness benefit for a significant period of time makes an application it may not be granted because the Treating Doctors Report (TDR) will not be accurate. If "reactive/environmental" depression (depression that appears to have been caused by a particular event in the person's life) is the diagnosis then given treatment and the resolution of the triggering problem, it is not unreasonable to have a TDR which states that the person may recover sufficiently to be able to work within 2 years; consequently they will not qualify for DSP - see clause 11 of the preliminary guidance notes below. But if, as in my case, the correct diagnosis is actually BP, (BP depression can still be triggered by life events, but may continue after the "problem" is resolved) then they will not be receiving the correct treatment and the TDR will be incorrect as to diagnosis, treatment plan and potentially the outcome 2 years hence. In my own case, I first came in contact with the Mental Health profession when I was 22 and presented with

performance anxiety during exams, it took another 8 years for me to be diagnosed correctly. Obviously I have other issues which can present as a diagnosis in themselves but which in reality are associated symptoms of the BP.

The requirements in clause 9 work against someone without a correct diagnosis, or who has not been assessed fully by a professional.

To some extent this problem is difficult to resolve, a JCA can only act on the information available at the time, but there are definitely some people whose actual functioning capacity would qualify them for the DSP who will not receive it because inaccurate information was provided to Centrelink about the applicant on the TDR.

Another issue which came up in the Ombudsman's report is the problem with people not acknowledging that they have a MI – they know and admit they are not well and cannot work, but won't admit to themselves or others that they have a diagnosable illness. Associated to this is the person who has a diagnosis but is so ashamed or feels so stigmatised by the diagnosis that they won't disclose it. There are also a small number of people who see a MH professional and receive treatment but do not know their actual diagnosis. I discussed this with my own psychiatrist, and he said he has seen people who would be devastated, perhaps even suicidal, to learn that they had schizophrenia, so he treats them for their MI but doesn't discuss their diagnosis with them if possible. Sometimes a family member or carer know the true nature of the MI.

My doctor has worked for many years in both the public and private systems sectors. He has had opportunity to assess the nature of, frequency of and support for people with MI under the public system. He said he was constantly frustrated by the infrequency of people's appointments and the short duration of the appointments. These problems made it difficult to be sure of diagnosis, treatment plan and long term prognosis as he may only see the person for 15 minutes every couple of months. He had limited time and TDR's were difficult to complete in the expected timeframe with limited knowledge of the patient. There were also occasional logistical problems with files being in the wrong location, incorrect or out of date address details as patients often shared a friend's house for a time, were in boarding houses or were homeless. "Coach surfing" was also a common problem. This often meant that details could not be checked; forms were not received by the patient or were returned unopened. Many People have dual diagnosis with drug addiction common, this causes unreliability in appointment attendance for some people, and few of these people have consistent contactable phone numbers. These are all common logistical and practical problems experienced everyday by people assessing the public MH system. Yet they can have a significant impact on the correct diagnosis, treatment plan and compliance with the required regime and yet an even bigger effect on the persons likely health circumstances into in the future and the

assessment there of. It is difficult for professionals in the private sector and virtually impossible for those in the public sector to help some people with their paperwork.

Determining Impairment and Assigning Impairment Ratings

5. An impairment rating is only to be assigned after an appropriate history and examination have been undertaken.

6. An impairment rating can only be assigned if the medical condition and its resulting impairment (i.e. the functional effect on the person's capacity to work) are both permanent.

7. In this context permanent means the medical condition causing the impairment is a fully documented, diagnosed condition which has been investigated, treated and stabilised and is more than likely in light of available evidence to persist for more than two years.

8. A condition maybe considered stabilised if the functional effect of the person's medical condition on the person's capacity to work, is more than likely in the light of available evidence and after undertaking reasonable treatment to persist for more than two years.

9. In order to assess whether a condition is fully diagnosed, treated and stabilised, an assessor must consider:

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what treatment or rehabilitation has occurred;*

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whether treatment is still continuing or is planned in the near future; and*

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whether any further reasonable treatment is likely to lead to significant functional improvement in the next two years.*

10. Significant functional improvement is improvement that would enable the person to work within the next two years.

11. Impairments that are not permanent cannot be assigned an impairment rating under the Tables. For example, a medical condition causing impairment may last for more than two years but the resulting impairment level may improve and even cease

within two years – if this is the case, the impairment must not be assessed under the Tables.

There has been some recognition in the Advisory Committee's report and the draft Impairment Tables (IT) that mental illness (MI) is a "whole of life" problem. MI can be unpredictable, and the long term course of a MI is difficult to assess when first diagnosed - note I am not discussing misdiagnosis here. There is also inconsistency in the success of accepted management plans for a correctly diagnosed illness. Taking BP as an example - I believe after 25 years I could be classed as an "expert consumer" in relation to this disorder - the committee will be aware that the long term prognosis for many people with BP is quite positive, while one may never say that a person is cured of BP, it can be successfully managed, and the person can lead a relatively normal and successful life - given compliance with treatment/management plans and the absence of serious life events which would likely trigger an episode. BP can surprise you though - as the magistrates in NSW discovered - it can remain well controlled for years, and then reappear with dramatic life changing consequences.

Other sufferers – me included - have much greater difficulty living anything like a "normal" life. Despite showing the symptoms of MI in my late teens, I managed, with a couple of stumbles, to complete a law degree and work as a solicitor, progressing from a regional firm, to what is now the Melbourne office of an international firm by the time I was 30. My episodes were getting worse however, I was hiding my illness – still thought to be depression and anxiety - by blaming a back problem, which I have, but which was rarely the cause of my work absences. I used annual leave to cover for periods of hospitalisation. When I was offered an Associate partnership, I felt I had to disclose my illness. It was clear that I couldn't manage the extra pressure and expectation that my career path was taking, so I changed direction and took a position as in-house counsel with a regional financial institution. This lasted about 3 years before I crashed totally and had to resign. I have not worked full time since 1991.

The course of BP in my case is at the serious/chronic end of the spectrum. with Over the course of my life I've made 4 suicide attempts, had at least 35 inpatient admissions (I estimate that I've spent more than 2 years of my adult life in psychiatric hospitals), 76 ECT treatments and been prescribed at least 30 different medications, in the hope of finding a drug regime that would alleviate my symptoms for more than a few weeks. I have also attended courses in Cognitive Behavioural Therapy, Group Therapy and one on one psychotherapy and yet I have not obtained a significant symptom free period. I see my general psychiatrist weekly, this is necessary because my moods, and other symptoms, can fluctuate rapidly. I also see a psychiatrist specialising in psychotherapy regularly. As well as the more "normal" and accepted symptoms, depression and mania I experience mixed state episodes - where both depression and mania are present

simultaneously -this is very unpleasant; not at all like the euphoric manias popular perception attaches to BP and much harder to treat successfully.

The longest period I have been "well" in the last 20 years is about 6 months. My case is a good illustration of how a one size/rule fits all approach cannot be adopted for a particular illness. The commonly held belief that medication controls BP is not true, in a significant number of cases, particularly for those people who experience more depressive episodes than manic ones; control is not always successfully achieved. For most people mania can be effectively managed with the currently available anti-psychotics however, for many finding an appropriate and effective anti-depressant is much more difficult. Care must be taken to ensure that individual cases are assessed on their own merits and that standardised assessment values are not applied for a particular condition. The IT and JCA's must have flexibility, there is a general tendency to categorise functioning for a condition in a standardised way and it's not appropriate for MI.

It has been established beyond doubt that working is a positive psychosocial activity, and that getting people back to work can often assist in the overall recovery process however the pressure, perceived or actual can have a very negative effect. In my case I find it incredibly frustrating having the desire to work, the training to do something worthwhile and not have the stability to do it. It goes without saying that with my background, I would be significantly better off financially if I could work. My last full time job - 1991 paid \$86,000 had I been well enough to continue on my original career path my salary, and financial position, nearly 20 years later would be significant. DSP is not my first choice, yet there is an attitude amongst policy makers, the media and the public at large that many people on DSP are bludgers who feign illness to avoid work. I can assure you that is not the case with me, and many others I have met with MI. The stigma attached to receiving the DSP is bad enough, having the added stigma of MI as well is very disheartening.

I have undertaken a number of projects, similar to this submission, for organisations and for my own sense of contributing to the community in some way. The benefit with this sort of work is that I can do it from home, when I'm having a good day or even a few good hours. The internet, email and teleconferences are my life savers in this respect. But jobs like this are rare and often come up when I'm not well enough to be able to guarantee meeting a deadline, I recently had to refuse a job offer - for which I would have been ideally suited, from an expertise standpoint, because it was 20 hours a week in the office. It was not possible to reduce the hours or perform it from home. Even though I was in a relatively well period at the time, there was no way I could guarantee the potential employer that I would be well enough to turn up every day. As client support was involved I had to be reliable. We agreed that someone else should be

appointed. I tried a 6 hour every Thursday afternoon and evening position with a Legal Centre coordinating clients and volunteer solicitors but I was missing about 1 in 4 Thursdays so I had to stop that job as well. I find that when I am well enough to undertake some form of paid employment, or even on a voluntary basis, the pressure of having to perform at the expected level at all times is just too much and results in me crashing back into depression that can last for weeks or months. Both my psychiatrist and my wife support the theory that doing some useful work is of great benefit to me psychologically but fear the negative side effects outweigh the positive possibilities.

Research indicates that placing people in the wrong jobs for their condition, such as significant contact with the public, tight time frames for completion of tasks or complex tasks which require significant concentration to complete, may be detrimental to their health, could lead to not just cessation of employment, but also cause deterioration in their level of "wellness". A related issue is job retention. The IT must provide scope for the JCA to consider, not just the abilities on the day of application, but also consider the likelihood of the person retaining the position for 3 or 6 months. There is significant research on this problem as well. The negative feelings generated by failure at work, both for the person with MI and those in the workplace are difficult to overcome and the effort it takes to get oneself psychologically ready to work again may take many months.

The issue of stability, periods free from symptoms, an apparent recovery is a vexed one. It needs to be treated with caution in the development of the impairment tables and in their application.

Another issue that impacts on functioning is the effect the medications we have to take have on our ability to perform even basic tasks. This is usually a physical problem, there may be significant drowsiness, making the operation of machinery or driving a dangerous proposition. People are almost conditioned to ignore the warning labels on medication packs – in this category I place policy makers, Centrelink staff, JCA and the public generally - as the medications generally taken by Joe Public, in reality, cause little difficulty. This is not the case with many psychotropic drugs. Most of the anti-psychotics at therapeutic doses do cause significant drowsiness, and vagueness, and slowing up of executive function. Why take them? Because the symptoms they help reduce are more distressing than the than the side-effect they cause. In my case, the dose of anti-psychotic I take is symptom dependent. I will frequently doze off when sitting at the computer or reading I have even fallen asleep on the toilet and while standing up. Obviously driving or any other activity involving machinery is out of the question at these times. There have been occasions that due to family circumstances I have had to drive short distances, apart from the risk of sleeping while the car is moving, I can fall asleep at traffic lights. Medication side effects are very significant for a number of people. But it's a very individual sort of thing; some people can tolerate 1000 mg of an anti-

psychotic without falling into unconsciousness while others will sleep for 10 hours on 100 mg of the same drug. The drowsiness problem is one of the reasons some people are non-compliant with medication regimes, others being the incredible weight gain some medications cause, or the loss of sexual function. This is a problem with maintenance levels of medication, particularly anti-depressants which are used to support a level of functionality and prevent reoccurrence of the depression. This can cause significant relationship issues, and because of this problem people sometimes go off their medications to "save their relationship". Some people will stop taking medication because of a feeling of being in a chemical straight jacket – this is often a problem for people with BP who experience euphoric, artistic or highly productive mania. It would be inappropriate for a JCA to apply the IT in such a way as to ignore these issues.

The signs and symptoms of psychiatric impairment may vary over time. Assessors should not rely on a 'snapshot' or once-off assessment.

For psychiatric conditions that are episodic or fluctuate, the assessor should apply the rating that best describes the person's functional abilities on most days/most months.

Current trends in policy and the attitude is community MH professionals and Government policy today in relation to MI are "recovery focused", with treatment plans put in place to assist the MI person to return to becoming a functioning member of society

I do have periods where I am relatively "well" and function "normally" in my day to day life. I answer the door or the phone, I come out of the bedroom and mix with the family, my self-care is appropriate in that I shower and eat proper meals, I am able to get groceries from the supermarket or medication from the chemist, I can pick the children up from school. I am able to attend psychiatrist appointments without a driver and support person. Likewise I could attend a JCA interview although it may cause enough stress to spark a relapse.

The first 3 dot points of the introduction to the draft IT are problematic and are to some extent qualified by the final 3, but where is the emphasis going to fall? The final 3 points should be an overriding proviso to guide the JCA about the difficulties with calculating a points score for a MI. What about the person who has not been diagnosed because of the waiting list at the Community Mental Health Service, or the difficulty in finding a GP who bulk bills or one who has more than a rudimentary knowledge of MI. Also obtaining and attending an appointment with an acceptable medico require the ability to initiate, to be decisive to take control of a situation and act in a positive purposeful manner. That is often quite contradictory to the abilities of a person suffering from MI. Even if you they have a friend, family member or welfare worker to help link up with these services,

or meet Centrelink's requirements often government and NGOs will not discuss the case the anyone other than the claimant. It can be very difficult if not impossible to comply with these demands if you can't get out of bed, interact with others or meet basic self-care standards. When you are particularly unwell dealing with the mail is a task often left unattended and communications from Centrelink may never be opened, I have been in hospital with people who believed that the Centrelink office is a mind control centre where you will be brainwashed or operated on. Centrelink is a powerful and threatening organisation for many people with MI. It controls their lives, if they don't do what it says when it says and meet their arbitrary standard, you will not receive your DSP and therefore become destitute. This will result in the loss of the hope needed to continue living with MI.

I trust the foregoing is of some benefit to the committee.