

**Submission**  
**The National Advisory Council on Mental Health**  
**Inquiry into Income and Living with Mental Illness**



**July 2010**

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To The National Advisory Council on Mental Health

**'Daily Bread, Income and Living with Mental Illness'**

The NSW Consumer Advisory Group – Mental Health Inc. (NSW CAG) is the peak, independent, state-wide organisation representing the views of mental health consumers at a policy level, working to achieve and support systemic change. Our vision is for all mental health consumers to experience fair access to quality services that reflect their needs.

NSW CAG recognises the significant impact that low incomes and a lack of financial resources have on the quality of life and health for people experiencing mental health problems.

We would like to offer the following observations and recommendations from our core work of hearing from mental health consumers about their experiences.

We are also providing a submission to the Disability Employment and Insurance Scheme in August which will provide a more detailed response relevant to the National Advisory Council on Mental Health's request for information. We also refer you to previous submissions by NSW CAG (available at [www.nswcag.org.au](http://www.nswcag.org.au)) which cover many of the issues relevant to your inquiry.

Please find attached in particular submissions in response to:

- The National Mental Health and Disability Employment Strategy
- The National Disability Strategy and
- The Pension Review

Please do not hesitate to contact me on any questions that you may have.

Yours sincerely,

Karen Oakley  
Executive Officer

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## **Basis of this advice**

NSW CAG exists to ensure that policy makers hear the perspectives of mental health consumers<sup>1</sup> across NSW. To enable our representation of mental health consumers and to advocate for systemic change, NSW CAG elicits information from

- Over 1000 people on our Network who are accessible via the internet;
- Face to face consultations with consumers within each Area Health Service across NSW.
- Our knowledge base derived from consulting with consumers of mental health services in NSW over the last 17 years.

## **Mental Illness and Income**

It is well known that low income can have a significant impact on people's health and wellbeing (Australian Institute of Health and Welfare, 2002).

NSW CAG regularly hears from people with mental illness who have different types of income, whether it is through a pension from Centrelink, employment or a combination of both. Many people express that despite access to such incomes they continue to struggle on a daily basis to make ends meet.

Many people are often forced to make choices between meeting basic needs, such as purchasing sufficient fresh food or medication, paying a bill, keeping the electricity connected, and participating in social or recreational activities. Consumers report that even activities such as going for a coffee with a friend, whilst important for their mental wellbeing, is, financially, a luxury.

One consumer, whose family is living off a wage assessed as too high to qualify for Centrelink assistance, discussed how she has:

*“resorted to hiding bills and not opening mail.. as I just can't pay them...I have had to disconnect the electricity in my name as Vinnies can only give so much...I have drained all my resources and am sick and tired of asking for things from my friends and family. It brings down your self-worth and makes you feel terrible”.*

(Consumer, NSW CAG Consultation, 2010).

Stress is associated with not only being unable to afford everyday items, but also not being able to invest in the future, whether that is for children's education or personal superannuation. This creates a strong feeling amongst consumers that their experience of poverty will continue into old age. One person stated:

*“...(when I become unwell) all the money I have saved when I am well often diminishes quickly because of my increased appointments with health care professionals and my increase in medications”.*

(Consumer, NSW CAG Consultation, 2010).

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<sup>1</sup> A person who experiences mental illness and uses or has used mental health services

It is also common to hear people report financial issues impacting upon their medication. One example of this is instances where lack of finances:

*“led to failure to maintain prescribed medication on a daily basis; purely as a result of not being able to afford it”.*

(Consumer, NSW CAG Consultation, 2010)

This is clearly a significant concern when it comes to the health and wellbeing of people who experience mental illness. It is very clear from our conversations with consumers that the current level of welfare or income for many is insufficient to meet their basic needs, with many people making quite serious decisions about which necessity to live without in order to get through.

### **Personalised Support Packages**

NSW CAG recommends that:

- Personalised support packages be person directed with options available for income management
- All support agency workers be provided with training and education to raise awareness and understanding about mental illness
- Service providers are trained to work from a recovery orientation
- Education to enhance peoples skills such as budgeting skills is made available to people

Many people who experience mental illness are able to participate fully in society and live meaningful and fulfilling lives. However for many the impact of having a mental illness can mean life choices and quality are reduced. NSW CAG acknowledges that there are different levels of need and therefore an individualised approach must be taken in creating support packages for people with mental illness. Such supports need to consider the financial and health needs and psychosocial disability that is unique and varies in degree for each individual. Support also needs to come in the form of education about support options available to people and skill specific training for example, in budgeting or interview techniques for obtaining employment.

Consumers strongly support the idea of personalised support packages, especially person directed schemes. Having options and choice in service provision is an important issue for people, and it is believed that such a scheme will increase their ability to tailor options that best support their mental health and lifestyle needs. This type of scheme also acknowledges that each individual is different and therefore has different needs.

Consumers have also identified that the people who deliver support services need to have a stronger understanding of mental illness. NSW CAG regularly hears about incidents of consumers encountering stigma and discrimination from the service providers that are meant to support them.

*“I found that the companies contract to help me ‘overcome my barriers to employment’ were useless, insulting, rude and stigmatizing. They wasted my time and on several occasions actively prevented me from seeking employment...”*

(NSW CAG, Consultation, 2010)

To eliminate such experiences, NSW CAG recommends that agency workers receive appropriate mental health education to reduce stigma, and that they are trained to work from a recovery orientation. Recovery orientation emphasises that recovering from illness is a very personal journey that is different for each and every person (Meehan, King, Beavis & Robinson, 2008). It is a holistic approach to illness, noting that social, economic, education, employment, housing and other needs are as important as addressing psychological and medical needs. The focus is on the individual and their needs first, and on the illness, which is only one part of a person, second. Recovery orientation is not about being symptom-free or off medications. It is about living a meaningful life with hope for the future.

### **Employment and Employment Support Services**

NSW CAG recommends:

- Measures be put in place that enforce workforce guidelines which take into consideration the impact of mental illness, its intermittent nature, and that ensure that workplaces prohibit discrimination and are flexible in their approach to the employment of people who live with mental illness.
- Measures be put in place that ensure that Job Networks are regulated by an overarching agency, and provide at minimum standards of professional service where staff have knowledge of mental illness, and their service reflects this knowledge and encourages and supports those living with mental illness in seeking employment.
- That employment support service staff undergo ongoing training to ensure that they are working from a recovery framework, and provide services that support recovery.
- That employers and workplaces receive anti-stigma and mental health awareness and education.
- That employment support programs provide support and employment training that meets the specific needs of people with mental illness, such as how to prepare for interviews or how to discuss their mental health with employers.
- That the Government instigates a combination of education and incentives, to encourage employers to hire people with mental illness, and provide supportive and flexible workplace environments.

*Please refer to NSW CAG’s submission to the National Mental Health and Disability Employment Strategy for detailed information regarding this section.*

For many consumers of mental health services, opportunities for participation in employment, including, and often particularly, mainstream employment is an important aspect of their journey of recovery. Opportunities for participation in the workforce have a range of benefits for individuals, that include increased self-esteem and self-worth, confidence, and providing a purpose and meaning to life.

Participation in meaningful and satisfying employment also facilitates broader social participation and inclusion, providing avenues for social and leisure experiences, opportunities for economic participation, greater community involvement, and future security through superannuation and options for housing.

Consumers regularly report that they are capable of and want to work; however, they face many barriers in achieving this, including:

- Stigma, discrimination and lack of understanding from employment support agency workers and potential employers
- Limited options to undertake meaningful employment opportunities
- Limited support once employment or training has commenced
- Financial limitations that are imposed by hours worked under the Disability Support Pension and eligibility for a health care card and
- Inflexible workplaces

*“employment agencies invariably don’t get just how tough it is with schizophrenia - especially the vulnerability to stress. Maybe the government needs to realise we are capable workers within our constraints”.*

(Consumer, NSW CAG Consultation, 2009)

Many consumers report that when they commence employment or training, they cease to receive any continuation of support during this time. They advise that having ongoing support or *“even a phone call”*, whilst doing training, or once employment has been obtained, would substantially reduce stress and anxiety during this transitional time.

The importance of having support from mentors who have been through similar experiences has also been emphasised as a way for consumers to feel more comfortable at work.

Consumers also note that their mental health condition can affect their ability to present well in interviews, and believe that they would benefit from interview training and support programs specific to people with mental health conditions. One individual stated that:

*“I didn’t know how to present myself to best impress due to the depression I was feeling inside. I would have benefitted from some kind of training or support on interview and preparation for interview skills best suited to people with my condition”.*

(Consumer, NSW CAG Consultation, 2010)

NSW CAG believes that for any employment program to have maximum impact on the obtainment of employment in appropriate and flexible working

environments, it needs to be combined with a government initiative to promote supportive workplaces and reduce the stigma that prevents people with a mental illness from being hired in the first place. As one consumer described her job hunting experiences:

*"I was frightened to discuss it, worried about stigma and terribly paranoid about the reaction of potential employers".*

(Consumer, NSW CAG Consultation, 2010).

## Centrelink

NSW CAG recommends that:

- The initiative to make Centrelink more accessible and flexible to people who experience mental health problems, including reduced red tape, and making information and forms simple to understand and complete. It is also recommended that information is presented in many different formats, and that access to verbal support is available.
- The directive to ensure that people living with mental illness have security in accessing the DSP in times of illness, and are encouraged to work.
- The work hour threshold for DSP or other suitable pensions be reinstated from 15hrs/week to 30hrs/week.
- A system is put in place that allows people who have previously been on a pension but have moved into the workforce, to be reinstated in a prompt and timely manner should they lose their employment or become unwell.

*Please refer to NSW CAG's submission to the National Mental Health and Disability Employment Strategy page 6 for further information.*

Consumers have also identified the system of fortnightly reporting employment income to be a source of stress and anxiety. Consumers view that this system creates significant uncertainty about their payment and prevents effective budgeting. Consumers put forward alternative proposals, such as Centrelink assessing payments based on the previous 6 months' earnings, similar to Housing NSW rent assessment. One consumer commented that if such a scheme was implemented:

*"I would be able to budget a little better. The uncertainty and stress around money issues would be lessened".*

(Consumer, NSW CAG Consultation, 2010)

## Pharmaceutical Benefits Scheme

NSW CAG Recommends:

- A review of the PBS scheme to :
  - assess increasing the cap to increase the number of people who can access the scheme
  - increase the number of medications available for the treatment of mental health conditions.

While many consumers are highly appreciative of the support that they can receive through the Pharmaceutical Benefit Scheme (PBS), many report that it is still insufficient to fully address their needs.

Consumers report incidents of medication prescribed for their condition not being listed on the PBS. In some cases, the medication is listed on the PBS but not for the medical purpose that a person requires it, thus leaving affordable medication just out of their reach. An example of this is medication such as Zyprexa (Olanzapine) which is only available on PBS to people diagnosed with bipolar disorder or schizophrenia but has been found useful in the treatment of anxiety disorders, panic disorders and anorexia nervosa (Hollifield, Thompson, Ruiz & Uhlenhuth, 2005; Nemerfoff, 2005; Powers, Santana & Bannon, 2002) or Lamotrigine, which is listed on the PBS for use in the treatment of epilepsy, but has been found extremely effective in the treatment of Bipolar Disorder (Calabrese et al, 2003; Calabrese et al, 1999).

*“a person’s choice in consultation with professionals and treatment options (should) not create hardship for that person”.*

(Consumer, NSW CAG Consultation, 2009)

## Individual Advocacy

NSW CAG recommends:

- That an independent individual advocacy service for mental health consumers be established.

A strong reoccurring issue for mental health consumers is the need for independent individual advocacy services. People frequently report issues with liaising and negotiating with Government services such as Centrelink, Housing NSW or the legal system, as well as with the private agencies such as banks, electricity companies and other service providers.

Many consumers report that due to their limited financial income they frequently get into financial difficulties, and having independent assistance to help negotiate repayment plans and bill payment extensions would be of significant

benefit. This would both reduce financial hardship, and reduce the levels of stress and anxiety being experienced by mental health consumers in relation to their finances. Having available support such as this would also reduce the number of people who are left in situations where their tenancy or utilities are at risk, or they are left to choose between purchasing food or their medication.

## References

- Australian Institute of Health and Welfare (2002). Australia's Health 2002; AIHW, Canberra
- Calabrese, J. R., Bowden, C. L., Sachs, G., Yatham L. N., Behnke, K., Mehtonen, O. P., Montgomery, P., Ascher, J., Paska, W., Earl, N., & Devaugh-Geiss, J. (2003). A placebo-controlled 18-month trial of lamotrigine and lithium maintenance treatment in recently depressed patients with bipolar I disorder. *Journal of Clinical Psychiatry, 64*(9) 1013-24.
- Calabreses, J. R., Bowden, C. L., Sachs, G. S., Ascher, J. A., Monaghan, E., Rudd, G. D. (1999). A double-blind placebo-controlled study of lamotrigine monotherapy in outpatients with bipolar I depression. *Journal of Clinical Psychiatry, 60*(2) 79-88.
- Hollifield, M., Thompson, P., Ruiz, J., Uhlenhuth, E. H. (2005). Potential effectiveness and safety of Olanzapine in refractory panic disorder. *Depression and Anxiety, 21*(1) 33-40
- Meehan, T., King, R., Beavis, P., Robinson, J. (2008). Recovery-based practice: Do we know what we mean or mean what we know? *Australian and New Zealand Journal of Psychiatry, 42* 177-182.
- Nemeroff, C. (2005). Use of Atypical Antipsychotics in Refractory Depression and Anxiety. *Journal of Clinical Psychiatry, 66*(8) 13-21.
- Powers, P., Santana, C., Bannon, Y. (2002). Olanzapine in the treatment of anorexia nervosa: An open label trial. *International Journal of Eating Disorders, 3*(2) 146-154