



# **A Welcome Change**

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**SUBMISSION BY CARERS NSW IN RESPONSE TO THE RELEASE  
OF THE MENTAL HEALTH BILL 2006 - EXPOSURE DRAFT**

**NOVEMBER 2006**

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# 1. EXECUTIVE SUMMARY

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## 1.1 Introduction

Carers NSW (CNSW) is the peak body representing 750,000 carers in this state. Carers are usually family members or friends of any age who provide unpaid care and support to people with a mental illness, disability, chronic condition or who are frail aged.

This submission was developed by CNSW in response to the release of the Exposure Draft Mental Health Bill 2006.

In developing this submission, CNSW listened and carefully considered the significant amount of feedback received from carers through the organisation's various programs. CNSW also consulted with staff from the Carers Mental Health Program and other peak associations representing important stakeholders.

## 1.2 Key Issues

The Draft Bill includes important changes for the community care sector, particularly carers, with formal recognition of carers included within this legislation for the first time.

While this recognition is to be commended, CNSW has identified a range of issues regarding particular sections of the Draft Bill that require further consideration.

Apart from some concerns noted around language and terminology, the majority of these issues focus on the need for more detail within the clauses and sections that relate to carers and their right to access appropriate information and be included in treatment and discharge planning. Without this detail, there is a risk that the recognition afforded to carers within the Draft Bill will have little meaningful impact.

### Language and Terminology

While the Draft Bill is more user friendly than the original 1990 Act, there are a number of instances where awkward phrasing or inconsistent wording could lead to misinterpretation by services. The need for uniformity of language and clear phrasing is key to the ability of mental health staff to understand and interpret relevant legislation, supporting consistent practice between services.

### Principles for Care and Treatment

The last clause in the Principles for Care and Treatment (Section 68) notes the role of carers and their right to be kept informed. However, the clause does not include enough detail to adequately explain what these rights are or how mental health staff should uphold them.

### Definition of a Primary Carer

While the definition of a primary carer (Section 71) seeks to provide clarification about who can be recognised as a carer, it does not take account of the fact that there could be more than one carer – of particular relevance to cultures such as Aboriginal and Torres Strait Islander, where caring is often a shared responsibility. There is also no recognition that a carer could be a child or young person, even though approximately 14.8% of carers are under 26 years of age (ABS Survey for Disability, Ageing and Carers, 2003).

### Nomination of Primary Carer

Review of the section that focuses on nomination of a carer (Section 72) identified the need for a clear process for nomination. CNSW also believes that a new section should be incorporated here which deals with assessment of the caring situation – including the

carer's capacity and willingness to care as well as their emotional, mental and financial needs.

### **Notification to Primary Carer**

Sections that relate to notifying the carer (Section 75,78 and 79) about significant steps to be taken in relation to the consumer's treatment, including discharge, stipulate that staff 'must take all practicable steps' to contact or inform carers. CNSW argues that this phrase needs to be more prescriptive so that mental health staff are clear about their obligations. It is also proposed that a care plan be developed for carers, which takes account of the outcomes of the care situation assessment and includes a plan for crisis intervention.

### **Administrative Objectives and Functions**

CNSW believes providing consistent recognition of carers as part of the care team within the Draft Bill will support improved carer inclusion. As Section 105 defines the responsibilities and obligations of mental health services and Section 106 focuses on the functions of the Director-General, modification to clauses within these areas to further acknowledge the need to work in partnership with and provide training to carers is proposed.

### **Training and Education**

Once the Draft Bill is passed, all stakeholders, including consumers and carers, will require training and education regarding the legislative changes and their impact. A 'train the trainer' approach should be utilised for mental health professionals to ensure expertise is retained within each service.

## **1.3 Recommendations**

- 1) Clearer articulation should be provided in Section 68 around the inclusion of carers (see Recommendation 4 below).
- 2) The phrase 'must take all reasonably practicable steps' should be replaced by the word 'must' to ensure mental health workers are clear about their obligations (also see Recommendations 12 and 13).
- 3) The phrase 'least restrictive environment' should be expanded to reflect the requirement for mental health professionals to take account of the needs of the carer, if one exists or has been nominated (see Recommendation 7). This phrase should then be used in a consistent manner throughout the Draft Bill.
- 4) The rights of carers to be informed, included, educated and consulted should be articulated within the Principles for Care and Treatment (Section 68) of the Act, in line with the detail accorded to consumer's rights within this section.
- 5) The word 'primary carer' in clause (1) of Section 71 should be modified to 'primary carer/s' to recognise that there could be more than one significant carer.
- 6) The wording in clause (1) (d) (ii) of Section 71 should be modified as follows to recognise the existence of young carers :  
Any person, including a child or young person, who is primarily responsible for providing support or care to the consumer (other than wholly or substantially on a commercial basis)
- 7) A further clause should be added to clause (d) of Section 71 to ensure that known care relationships are taken into account when defining the primary

carer/s:

(iv) Any person who has a known care relationship with the consumer.

- 8) A clear and well defined process for the nomination of a carer should be developed and provided in Section 72 that takes account of who can nominate a carer, the duration of time for which the nomination is in force, the capacity of the consumer when nominating and at what point in treatment nomination takes place.
- 9) A new section should be developed (following Section 72) which outlines the requirement to conduct an assessment of the nominated carer's capacity and emotional, mental and financial needs, with outcomes factored into the discharge care plan (see Recommendation 10).
- 10) A process should be developed and included in the new section (see above Recommendation 9) which details how and when the assessment of the carer's capacity and needs will take place and what alternatives are available should the carer be assessed as not capable of providing the care required.
- 11) Those clauses which use the phrase 'the best possible care and treatment in the least restrictive environment...' should be modified to 'the best possible care and treatment, taking into account the consumer's living situation, level of support within the community and the needs of their carer/s, where one exists or has been nominated, in the least restrictive environment to support safe and appropriate care....'
- 12) In Section 78 (1), the phrase 'must take all reasonably practicable steps' should be replaced with the word 'must' to make it clear to mental health services that they have an obligation to inform carers about the steps to be taken in relation to the consumer's treatment and discharge.
- 13) In Section 79 (1), (2) and (3), the phrase 'must take all reasonably practicable steps' should be replaced with the word 'must' to make it clear to mental health services that discharge planning must always involve the consumer's carer, where one exists or has been nominated.
- 14) In Section 79 (3), the phrase, 'including a care plan, which takes account of the outcomes of the assessment of current and future carer capacity and needs and includes a plan for crisis intervention' should be added at the end.
- 15) In clause (e) of Section 105 the word 'liaison' should be replaced with 'work in partnership with the carer, consumer, mental health professionals and service providers' to support carers to be recognised as equal partners within the care team.
- 16) The phrase 'including the primary carer/s, where one exists or has been nominated' should be inserted at the end of clause (d) of Section 106 to consolidate recognition of carers and ensure accountability for their training and education needs.
- 17) A training and education program that focuses on the changes made to the Act, and how these will affect services, consumers and carers, should be developed and implemented to support the release of the new Act in 2007.
- 18) A 'train the trainer' mode of delivery should be utilised to enable both existing and new staff to receive training as required and ensure expert knowledge

about the changes to the Act resides with senior mental health service staff, who can offer ongoing information and advice.

- 19) A timeframe should be established that provides guidance to mental health services regarding the completion of staff training and the effect of changes to operational policies and procedures.
- 20) A community awareness campaign should be devised and implemented which includes fact sheets and information sessions specifically for carers and consumers which outlines the changes to the Act and the impact such changes may have on their lives.

### **1.3 Conclusion**

CNSW believes adopting the recommendations outlined within this submission will support the Mental Health Act to provide a clear message about the role of carers and the requirement for health care services to include them.

Supported by education and training for mental health professionals and a community awareness campaign to support the provision of information to carers and consumers, these new legislative requirements will be instrumental in bringing about a welcome change in the level of carer participation and ultimately to improved outcomes for consumers and the mental health system in NSW.

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## **2. BACKGROUND**

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### **2.1 About Carers NSW**

#### **2.1.1 Who we are**

Carers NSW (CNSW) is the peak body representing 750,000 carers in this state. Carers are usually family members or friends of any age who provide unpaid care and support to people with a mental illness, disability, chronic condition or who are frail aged.

CNSW provides a range of services and supports for carers and the community, including :

- Education and training for carers, service providers and communities
- Emotional support, counselling and individual advocacy for carers
- Information, publications, resource development and delivery
- Policy development, research and advocacy
- Sector development and systemic change
- Service innovation, development and evaluation

#### **2.1.2 Who we represent**

Carers are usually family members who provide support to children or adults who have a disability, mental illness, chronic condition or who are frail aged. Carers can also be parents, partners, brothers, sisters, friends or children of any age. Carers may care for a few hours a week or all day every day. Some carers are eligible for government benefits, while others are employed or have a private income.

The Commonwealth Carer Resource Centre, a one stop information, referral, support and counselling service for carers, resides in CNSW's Sydney office, giving the organisation direct access to feedback regarding the concerns of carers.

**The Resource Centre receives upwards of 600 calls per month from carers across NSW and approximately 10% of these calls are from people who provide care for someone with a mental illness.**

Carers provide the bulk of support in the community to people with a mental illness and consequently they frequently deal with the public health system, both the acute and community services. It is vital, therefore, that carers are recognised by mental health professionals and that the legislation which underpins the mental health system in NSW takes account of the important role which carers play.

### **2.2 About this Submission**

#### **2.2.1 Rationale**

This submission has been developed by Carers NSW (CNSW) in response to the release of the Exposure Draft Mental Health Bill 2006 by NSW Health. The Draft Bill is the culmination of work undertaken as part of the Review of the Mental Health Act 1990, which commenced in February 2004.

As the peak body for those that provide unpaid care for people with a mental illness, disability, chronic condition or who are frail aged, CNSW has closely followed the review process and previously responded to both discussion papers released throughout 2004 – Carers and Information Sharing (DP1) and The Mental Health Act 1990 (DP2).

CNSW welcomes the opportunity to provide feedback on the Draft Bill, which it recognises as critical legislation that is fundamental to the operations of the mental health system in NSW.

### 2.2.2 Consultation

In developing this submission, CNSW :

- Reviewed the Draft Bill in conjunction with the Review of the Mental Health Act 1990 Report;
- Consulted with the CNSW Families and Carers Mental Health Program regional staff and their networks through a paper process as well as a face to face workshop;
- Attended a round table discussion organised by the NSW Council of Social Services (NCOSS) attended by other peak bodies and associations/groups that represented important stakeholders such as carers, consumers and service providers.

CNSW was also informed by the significant amount of feedback the organisation receives directly from carers of people with a mental illness.

The CNSW Sydney office houses the Commonwealth Carer Resource Centre, a one stop information, referral, support and counselling service for carers. The Resource Centre receives upwards of 600 calls per month from carers across NSW.

**Approximately 10% of these calls are from people who provide care for someone with a mental illness.**

In addition, CNSW works with carers through its Carers Mental Health Project (funded by the NSW Department of Health under the NSW Family and Carer Mental Health Program).

For the last four years, this project has been working in two regions of NSW - the South Western area of Sydney and the Central West of the state – providing education and training to carers (information on mental illness and coping skills for caring) and to mental health professionals and community service providers (on carer-friendly practice). Consequently, CNSW has an up-to-date knowledge of the issues for carers in these regions.

CNSW also recently received funding under the same program to provide individual support and advocacy as well as education to carers in the South East Sydney/Illawarra, Greater Western and North Coast Area Health Services over the next three years.

### 3. ISSUES AND RECOMMENDATIONS

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#### 3.1 Overview

There is now considerable evidence that the inclusion of carers within the acute, community and primary health setting has a range of benefits, improving outcomes for patients and reducing health care costs. For consumers, there is increased compliance with discharge plans and the prevention of readmissions; for mental health professionals, there is valuable information and feedback, which can contribute to effective planning and management.

Although there is a move within the mental health system towards involving carers as 'partners in care', there are still many reasons why they do not receive the information they need. These may relate to the ethical and legal obligations of mental health professionals regarding confidentiality and the need for consumers to provide 'informed consent' prior to the health team being able to share information about the consumer.

In many cases, mental health professionals are also concerned that involving carers more fully will take away from their ability to focus their time and energy solely on the consumer – who they perceive to be their only client.

*Mum has a case manager, but he doesn't help me much. He says that I'm not his client.*

Excerpt from Hearing our Voices, Stories from carers of people with a mental illness (Julie's Story), August 2000

Additionally, members of the mental health team may never have received training in how to deal with complex issues, such as confidentiality, and how to address the different needs of the consumer and the carer. Because of this, they lack confidence and so avoid giving any information, often citing confidentiality as the reason.

Not only does this leave many carers battling for information and advice about the person for whom they are caring, it also ensures that the needs of carers to enable them to effectively provide care are ignored.

In order to improve carer participation, and support mental health professionals to include them in the health care team, it is critical that this opportunity to refine the Draft Bill is realised.

By carefully considering the way in which carers can be recognised within the Mental Health Act, NSW believes that the vast contribution which carers already make to the mental health service system can be consolidated and extended.

#### 3.2 Language and Terminology

CNSW acknowledges that the changes to the way in which the Draft Exposure Bill is written makes it generally more user friendly than the original 1990 Act. However, there are still a number of issues regarding language and terminology that need to be addressed.

For example, the following clause from Section 68 requires more substantive detail – it is hard to understand and therefore open to individual interpretation.

**Principles for Care and Treatment (section 68)**

- (j) The role of carers for people with a mental illness or mental disorder and their rights to be kept informed are given effect.

Additionally, the phrase 'must take all reasonably practicable steps', used in a number of clauses around informing carers or discharging consumers (eg Section 75 (1), Section 78 (1)), is meaningless and, again, open to individual interpretation.

Individual interpretation of the Act by mental health workers has historically resulted in inconsistent practice between services across NSW.

For example, the staff of some mental health services interpret the provisions of the current Act to mean that no information at all can be given to carers, while staff at another mental health service disclose certain types of information to carers as a part of their standard practice.

Carers of people with a mental illness may already be under considerable pressure and receiving mixed messages from services through inconsistency of practice can only add to their emotional and mental distress, ultimately affecting the quality of care they are able to provide.

Consistency of language is also an issue within the Draft Bill.

In some areas, the Draft Bill refers to the 'patient' while in other areas the term 'person with a mental illness' is applied. CNSW believes that 'consumer' is a more appropriate term to use when referring to those people with a mental illness/disorder and would like to see this adopted within and across the Act. However, whatever term is agreed upon when referring to people with a mental illness/disorder should certainly be used uniformly.

Another inconsistency relates to the use of the phrase 'least restrictive environment'. In some areas, this is followed by 'to support safe and appropriate care' but in other areas it is not. As noted within 3.5 of this submission, CNSW believes the phrase should be expanded. However, whatever decision is made regarding modification of this phrase, it should be used in a consistent manner to avoid any confusion or interpretational errors.

**Recommendation/s :**

- 1) Clearer articulation should be provided in Section 68 around the inclusion of carers (see Recommendation 4 below).
- 2) The phrase 'must take all reasonably practicable steps' should be replaced by the word 'must' to ensure mental health workers are clear about their obligations (also see Recommendations 12 and 13).
- 3) The phrase 'least restrictive environment' should be expanded to reflect the requirement for mental health professionals to take account of the needs of the carer, if one exists or has been nominated (see Recommendation 7). This phrase should then be used in a consistent manner throughout the Draft Bill.

### **3.3 Principles for Care and Treatment**

#### **Section 68**

Since the vast majority of care for people with a mental illness/disorder occurs in the community, the role of the carer must be recognised, supported and acknowledged as key to the consumer's management of and response to their illness.

One of the most important principles of effective carer support, as identified by Carers NSW over the past 25 years (Carers Support, 2003), is the inclusion of carers at every stage of service planning and delivery.

While their caring role is generally accepted as paramount to the recovery and overall care and support of consumers, carers often feel that their knowledge and experience is not sufficiently acknowledged or used in health and care planning.

Additionally, gaining access to information to support their caring role has in many cases been reliant on individual interpretation of the Act by various mental health professionals rather than on clear legislation and consistent comprehension and application.

*It is essential that information is shared with carers/significant family members in relation to inpatient information and afterwards. This is especially important at the first assessment and diagnosis of mental illness.*

Comment from a carer at a recent training session for carers in the Greater Western Area Health Service

Encouragingly, there is considerable acknowledgment within the Review of the Mental Health Act Report (“the Report”) of the importance of sharing information with carers and including them in care decisions. However, this acknowledgment is not adequately reflected within the Draft Bill itself.

For example, the inclusion of carers within the Principles for Care and Treatment (section 68, (j)) is an improvement, but does not provide the prominent and detailed recognition of the importance of the carer’s role that CNSW believes is required.

**Principles for Care and Treatment (section 68)**

- (j) The role of carers for people with a mental illness or mental disorder and their rights to be kept informed are given effect.

Further, there is no real articulation within the Act of the carer’s rights that are to be ‘given effect’. These rights need to be defined so that mental health professionals are aware of their obligation to ensure carers are provided with adequate information about diagnosis, medication, treatment and recovery to enable them to provide quality care.

While it could be argued that the Act is not the appropriate place in which to provide such definition, CNSW asserts that outlining the rights of carers and consumers in one document will support mental health workers to take a consistent approach to upholding these rights.

**Recommendation :**

- 4) The rights of carers to be informed, included, educated and consulted should be articulated within the Principles for Care and Treatment (Section 68) of the Act, in line with the detail accorded to consumer’s rights within this section.

### **3.4 Definition of Primary Carer**

#### **Section 71**

CNSW believes that providing a definition within legislation of a ‘primary’ carer should rightly be acknowledged as a key outcome of the Mental Health Act Review.

Not only does it provide real recognition of the substantial role that the carer plays in the health care team, it also gives credence to the need for carers to receive information about the consumer and contribute to treatment and discharge planning.

However, some review and refining of this section is required to provide further clarification around who a primary carer can be.

In considering the notion of a 'primary carer', it should be accepted that care is often provided to consumers in a family setting and could involve both parents and siblings as well as aunts, uncles, cousins and other relatives. This is particularly true for consumers and carers from cultures such as Aboriginal and Torres Strait Islander, who believe caring is the responsibility of the family as a whole rather than the responsibility of one individual family member.

The very singular and prescriptive wording used within the first line of clause (1) of Section 71 could then be problematic for this group, and other cultural sets.

**Primary carer (section 71)**

(1) The *primary carer* of a person (the *patient*) for the purposes of this Act is.....

Restricting the primary carer to one person also raises issues around the provision of information to the consumer's family and their inclusion within treatment and discharge planning. If the person noted as the 'primary carer' cannot be contacted or is not available due to health or other issues, mental health staff are under no obligation to make further efforts to contact or include other people who may be involved in the consumer's care.

CNSW would also like to see the concept of a 'known carer or caring relationship' included to give some additional protection and support to consumers by guarding against the discharge of patients into the care of a disinterested relative. While the prevalence of this scenario is not known, anecdotal evidence provided to CNSW suggests that this certainly occurs.

**Young carers**

CNSW believes that all children deserve a childhood that is free of adult responsibilities, such as caring for someone with a mental illness or disorder. However, in many cases, the child or children of a parent with a mental illness provides a substantial proportion of the consumer's care.

In Australia, young carers have been identified by services as being as young as 6 years of age, and just under half of young carers are below 18 years of age.

According to the 2003 ABS Survey for Disability, Ageing and Carers (unpublished data), 1 out of 6 carers in Australia (approximately 14.8%) are under 26 years of age. Of these carers, approximately one quarter provide care for someone with a mental illness.

However, the Final Report of the Young Carers Research Project (September 2001) notes that services "do not seem to be aware that young carers exist" and that even if young carers are identified, health professionals do not know about their unique needs or how to meet them.

*...I have been helping to care since I was 13....when I was fifteen, my brother moved out and I became the main carer for Mum. I was like a parent to her.*

*Its only over the last year that I've got the doctors and nurses to talk to me, but I've had to push them to do it. I guess they thought I was just a child, but I have been the main carer for Mum for quite a while now.*

Excerpt from Hearing our Voices, Stories from carers of people with a mental illness (Julie's Story), August 2000

If this trend is to change, consideration must be given to including some reference to young carers within the Draft Bill.

While the definition of a primary carer in the Draft Bill currently *allows* for the carer to be a young person or child (clause (1) (d) (ii) of Section 71), it does not formally *recognise* this.

CNSW proposes that wording is inserted within clause (1) (d) (ii) of Section 71 (see below) that refers to the fact that a carer could be a person of any age, including a child or young person.

**Primary carer (section 71)**

- (1) The *primary carer* of a person (the *patient*) for the purposes of this Act is:
- (d) if the patient is not a patient referred to in paragraph (a) or (b) or there is no nomination in force as referred to in paragraph (c):
    - (ii) any person who is primarily responsible for providing support or care to the patient (other than wholly or substantially on a commercial basis).....

While this recognition is in itself slight, it establishes the existence of young carers and provides the impetus for their unique needs to be acknowledged and considered by mental health services.

**Recommendation/s :**

- 5) The word 'primary carer' in clause (1) of Section 71 should be modified to 'primary carer/s' to recognise that there could be more than one significant carer.
- 6) The wording in clause (1) (d) (ii) of Section 71 should be modified as follows to recognise the existence of young carers :  
Any person, including a child or young person, who is primarily responsible for providing support or care to the consumer (other than wholly or substantially on a commercial basis)
- 7) A further clause should be added to clause (d) of Section 71 to ensure that known care relationships are taken into account when defining the primary carer/s:
  - (iv) Any person who has a known care relationship with the consumer.

### **3.5 Nomination of Primary Carer**

#### **Section 72**

As with Section 71, the development and inclusion of this section within the Draft Bill is an important breakthrough in the recognition of carers. However, some valid points have been raised about its application.

Of most concern is the lack of parameters around the actual process of nomination. Who can nominate, how the nomination will occur, and at which point within the consumer's treatment, are crucial questions that Section 72 does not currently answer.

In considering these, the current capacity of the consumer must also be taken into account.

The ability of the consumer to make a rational or appropriately informed decision will have a significant impact on the nomination process. Decisions made by the consumer while they are experiencing an episode of illness are often quite different to the decisions made when they are well and any process for nomination of a carer would need acknowledge this.

*I believe that the (current) Mental Health Act is wrong. It works well when people are well and can make their own decisions, but it doesn't work very well when people are ill. When a person is unwell, they can't make their own decisions.*

Excerpt from Hearing our Voices, Stories from carers of people with a mental illness (Jan's Story), August 2000

Additionally, the length of time the nomination is valid must be articulated if both the consumer's and carer's needs are to be met. While clause (5) of Section 72 refers to 'regulations' which prescribe the period of time the nomination must remain in force, there is no explanation as to what these regulations are or where they can be found.

**Nomination of primary carer (section 72)**

(5) A nomination remains in force for the period prescribed by the **regulations** or until it is revoked in writing.

Although the inclusion of Section 72 within the Draft Bill is to be commended, further thought must be given to developing an appropriate process that mental health services can easily interpret and apply, and which takes account of the issues outlined above.

**Assessment of caring situation**

CNSW believes that nomination of a carer by the consumer must be followed by assessment of the carer's capacity and willingness to provide the care required as well as the information, education and support needs they may have in relation to their caring role.

Discharging a consumer into the care of someone who is new to caring and may be in a state of shock, or who is exhausted from providing ongoing care, can have a significant impact on outcomes for both carer and patient. Additionally, carers who are unprepared for the work and stress involved in caring may find it difficult to cope, resulting in withdrawal of their support for the consumer at a critical period or their inability to continue to care due to health and wellbeing problems of their own.

There is often an assumption by mental health professionals that carers are able and willing to take on and continue in a caring role, without any assessment, either formal or informal, of their interest or ability to do so. While many carers enjoy caring for their loved ones and see it as a natural part of a close relationship, carers must be given a choice about caring and their choice must be supported and respected by mental health services.

Continued and regular assessment of a carer's capacity, willingness and needs is also essential. Currently there is no requirement for such assessment and, consequently, no system to gauge the carer's ongoing health and wellbeing. As a carer's emotional, mental and financial needs change over the course of their caring role, it is essential to monitor and assess these needs on a continuing basis to ensure adequate support is provided when and as required.

This is particularly important for those at either end of the carer age spectrum - young carers and ageing carers.

Young carers often experience varying needs and levels of disadvantage as carers as they go through different phases of their own growth and development. Often the 'hidden' army of caring within the community, children and young people are generally not recognised as primary carers by the mental health system and yet have the greatest need for assessment and support.

Ageing carers will be facing their own health and wellbeing issues as well as concerns around who will take over the care role when they are no longer able to act in this capacity.

In the United Kingdom (UK), the National Service Framework for Mental Health, which sets out the standards the Department of Health expects from its mental health services within the UK, goes some way to addressing this issue. It states that all individuals who provide regular and substantial care for a person should have an assessment of their caring, physical and mental health needs, repeated on at least an annual basis.

Mental health services in NSW need to take a similar approach and ensure that appropriate mechanisms are in place to assess the ability of carers to manage care at home.

In line with this philosophy, those clauses which use the term 'least restrictive environment' (such as in clause (a) of Section 68 below) should be amended to reflect the need to take a range of factors into consideration, including existing caring relationships, when determining the best way to deliver care and treatment.

**Principles for Care and Treatment (section 68)**

- (a) people with a mental illness or mental disorder should receive the best possible care and treatment in the least restrictive environment enabling the care and treatment to be effectively given.

Resource pressures on mental health services mean that staff are often too keen to rely on carers to provide care in order to free up in-patient beds. The 'least restrictive alternative' can then become the justification for an overloaded service to discharge consumers back into the community in the hope that family and friends will take responsibility for care.

*Note : Carers NSW has developed a tool (the Carer Profile) which is designed to assist mental health services with assessment of carer needs.*

**Recommendation/s :**

- 8) A clear and well defined process for the nomination of a carer should be developed and provided in Section 72 that takes account of who can nominate a carer, the duration of time for which the nomination is in force, the capacity of the consumer when nominating and at what point in treatment nomination takes place.
- 9) A new section should be developed (following Section 72) which outlines the requirement to conduct an assessment of the nominated carer's capacity and emotional, mental and financial needs, with outcomes factored into the discharge care plan (see Recommendation 10).
- 10) A process should be developed and included in the new section (see above Recommendation 9) which details how and when the assessment of the carer's capacity and needs will take place and what alternatives are available should the carer be assessed as not capable of providing the care required.
- 11) Those clauses which use the phrase 'the best possible care and treatment in the least restrictive environment...' should be modified to 'the best possible care and treatment, taking into account the consumer's living situation, level of support within the community and the needs of their carer/s, where one exists or has been nominated, in the least restrictive environment to support safe and appropriate care....'

### 3.6 Notification to Primary Carer

#### Section 75, 78 and 79

The importance of notifying the carer, where one exists or has been nominated, of significant steps to be taken in relation to the consumer's treatment, including discharge planning, cannot be overstated.

Carers often have detailed and significant information or advice that can have an impact on the proposed treatment plan – particularly when the consumer may have a limited capacity to provide input themselves. Without taking this information into account, treatment and discharge plans for the consumer may ultimately be flawed, resulting in non-compliance and possible readmission.

As noted within 3.2 of this submission, the phrase ‘take all reasonably practicable steps to notify the primary carer’ is very broad and open to interpretation. Any reference to informing or notifying the carer must be more prescriptive if mental health service staff are to clearly understand and act on their obligations to consumers and carers.

Ideally, the wording within the Draft Bill in relation to notification of carers should mirror the wording used in Section 76 (1), as noted below, which uses the verb ‘must’ when noting when a mental health worker needs to notify a consumer regarding a mental health inquiry.

#### Notification of mental health inquiries (section 76)

- (1) An authorised medical officer **must** notify an assessable person in the mental health facility that...

Additionally, the wording in Section 78 must clearly stipulate the need to inform the carer, where one exists or has been nominated, *before* any ‘event’ affecting the consumer is taken – not when it is happening or after it has occurred. This is particularly important when considering the discharge of a consumer that resides with their carer or is reliant on them for day to day care.

#### Discharge Planning

As noted in 3.5 of this submission, under Assessment of Carer Capacity and Needs, services are often under resourced, encouraging staff to discharge consumers into the care of a family member or friend.

*There needs to be a more cooperative approach to caring for people. As the health system is now, the buck stops with the carer. Its too easy for the health system to say “this person is too hard” and then just send them home to the carers.*

Excerpt from Hearing our Voices, Stories from carers of people with a mental illness (David’s Story), August 2000

Not only does lack of involvement in discharge planning for the consumer have immediate consequences regarding the viability of such a plan, it may also leave the carer feeling inadequately prepared to take up the caring role.

Prior to discharge of the consumer, the carer, if one exists or has been nominated, may require specific training regarding the medical needs of the person they support in the community, particularly when treatment is first commenced or, alternatively, when the consumer’s needs change or increase. Additionally, they may require referral to other supports that are specific to carers, including provision of emotional support or respite care to enable them to take a break from their caring role.

Another important factor for carers is the cost associated with caring for the consumer. Direct costs associated with their caring role may include transport costs, heating or cooling for the comfort of the person they are supporting or purchase of medical supplies. Indirect costs may include their limited access to employment and education opportunities while they are caring.

By involving carers in discharge planning for the consumer, the needs of the carer, including the unique and diverse needs of young carers, can be taken into account to ensure the plan is realistic and manageable for all those involved in its implementation.

Accordingly, the phrase in Section 79 (3), which stipulates that the consumer and their carer should receive 'appropriate information as to follow-up care' should be broadened to ensure that carers receive a plan of care. Such a plan should take account of input from the carer along with the doctor, consumer and case manager, be age appropriate so that young carers can manage, and include a plan for crisis intervention.

**Recommendation/s :**

- 12) In Section 78 (1), the phrase 'must take all reasonably practicable steps' should be replaced with the word 'must' to make it clear to mental health services that they have an obligation to inform carers about the steps to be taken in relation to the consumer's treatment and discharge.
- 13) In Section 79 (1), (2) and (3), the phrase 'must take all reasonably practicable steps' should be replaced with the word 'must' to make it clear to mental health services that discharge planning must always involve the consumer's carer, where one exists or has been nominated.
- 14) In Section 79 (3), the phrase, 'including a care plan, which takes account of the outcomes of the assessment of current and future carer capacity and needs and includes a plan for crisis intervention' should be added at the end.

### **3.7 Administrative Objectives and Functions**

#### **Section 105**

CNSW considers Section 105 one of the key sections within the Draft Bill, outlining as it does the responsibilities and obligations of mental health services.

For this reason, it is critical that the wording in clause (e), which describes the relationship with carers, is reflective of the way in which their role should be regarded – as an essential component of the health care team. Currently, the clause states that mental health services will 'provide for liaison with carers'.

#### **Objectives of NSW Health (section 105)**

The objectives of NSW Health under this Act in relation to mental health services are to establish, develop, promote, assist and encourage mental health services that:

- (e) assist patients to live in the community through the provision of direct support and **provide for liaison with carers** and providers of community services.

The word 'liaison', according to the Cambridge dictionary, means 'communication between people or groups who work with each other'. While communication is important between mental health services and carers, CNSW believes a more appropriate word to use in clause (e) would be 'partnership'.

The word partnership implies equality between those involved – working together to achieve the same thing. In the context of caring for a person with a mental illness/disorder, such a partnership should involve carers, consumers and key staff, such as case managers, psychiatrists and other clinicians, acknowledging and respecting the skills and resources that all parties bring to the care team.

This change, while subtle, strengthens the vision of carers as equal partners in the care and treatment of their loved ones.

### **Section 106**

As noted consistently throughout this submission, carers must be recognised as part of the overall health care team if they are to provide the care and support that the consumer needs in the community.

As Section 106 deals with the functions and accountability of the Director-General, CNSW believes it is essential that carers are specifically noted when reference is made to those responsible for the care and treatment of consumers, as in clause (d) below.

#### **Functions of the Director-General (section 106)**

The Director-General has the following functions under this Act:

- (d) to assist in the training and education of persons responsible for the care and treatment of persons who are mentally ill or mentally disordered...

Specifically noting carers within this clause is not only important for the purposes of consistent recognition as part of the care team but also to confirm that carers must have the opportunity to receive training and education if they are to act as an effective care resource within the community.

Carers often report that they have to 'learn the hard way' - by trial and error - when providing care, rather than receiving the information and education they need to arm them with the knowledge and skills which their caring role requires.

*The doctors didn't help....because they didn't give us any education to prevent the escalation of episodes. There was very little communication between the doctors and my family.....*

*We might have been able to avoid many of Mum's episodes if we'd had information and education about her illness and strategies to cope with it.*

Excerpt from Hearing our Voices, Stories from carers of people with a mental illness (Suzy's Story), August 2000

#### **Recommendation/s :**

- 15) In clause (e) of Section 105 the word 'liaison' should be replaced with 'work in partnership with the carer, consumer, mental health professionals and service providers' to support carers to be recognised as equal partners within the care team.
- 16) The phrase 'including the primary carer/s, where one exists or has been nominated' should be inserted at the end of clause (d) of Section 106 to consolidate recognition of carers and ensure accountability for their training and education needs.

### **3.8 Training, Education and Awareness**

As noted throughout this submission, having clear and consistent legislation for the mental health sector that acknowledges the role of carers in care and treatment of the consumer is an important component in the delivery of quality care in the community.

However, without training to identify and explain the legislative changes to mental health staff and an education program to support staff to develop and implement new and more effective policies and practices, any real gains for mental health stakeholders will be lost.

CNSW asserts that development and implementation of a training and education program is vital to support the release of the new Act in 2007. Such a program should be delivered to all mental health services using a 'train the trainer' mode, with attendance mandatory by senior mental health staff and professionals. This approach will support services to establish an 'expert' who can provide training and education to both existing staff (immediately) and new staff (as required) as well as act as a point of reference for staff needing ongoing advice or information regarding the new Act.

The timing of the delivery of a training and education program is critical to ensure mental health services have adequate time to train their staff and prepare for the changes they may need to make at an administrative, policy and service delivery level. Additionally, consideration will need to be given to establishing a timeframe for the implementation of any changes which services may need to make in order to operate in accordance with the Act.

An awareness campaign should also be implemented to alert the community, and specifically carers and consumers, to the changes. Q & A Fact Sheets which provide relevant information about the impact for carers and consumers written in a simple, reader-friendly style should be made available in a range of community languages and subsequent information sessions held to provide further clarification.

#### **Recommendation/s :**

- 17) A training and education program that focuses on the changes made to the Act, and how these will affect services, consumers and carers, should be developed and implemented to support the release of the new Act in 2007.
- 18) A 'train the trainer' mode of delivery should be utilised to enable both existing and new staff to receive training as required and ensure expert knowledge about the changes to the Act resides with senior mental health service staff, who can offer ongoing information and advice.
- 19) A timeframe should be established that provides guidance to mental health services regarding the completion of staff training and the effect of changes to operational policies and procedures.
- 20) A community awareness campaign should be devised and implemented which includes fact sheets and information sessions specifically for carers and consumers which outlines the changes to the Act and the impact such changes may have on their lives.

## **4. CONCLUSION**

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CNSW acknowledges that the Mental Health Act is legislation that exists to govern the care and treatment provided to people with a mental illness/disorder. Further, CNSW understands that the major aims of the Act are :

- For mentally ill/disordered persons to receive the best possible care and treatment in the least restrictive environment; and
- To keep any interference with or restriction of the rights, dignity, and self respect of mentally ill/disordered persons to a minimum.

In considering these aims, the vital role of the carer within the mental health care support team must also be acknowledged.

Family and friends are increasingly providing a significant proportion of health care in the community, without pay and often with very limited support. Current trends in the health care system in Australia, including workforce shortages and the limited capacity of acute care systems which leads to early discharge from hospital, means there is greater reliance on carers than ever before. While current and future policy directions, both state and federal, are encouraging in their recognition of carers, change in legislation to support carers has been slow.

The Exposure Draft Bill is certainly a step in the right direction in better addressing some of the concerns which carers have expressed regarding their recognition and inclusion by mental health professionals. However, carers are keen to ensure that the new Act both supports them to continue in their caring role and empowers them to make the right choices for their families and loved ones.

CNSW believes adopting the recommendations outlined within this submission will enable the Mental Health Act to provide a clear message about the role of carers and the accountability of health care services to include them, leading to a welcome change in the level of carer participation and ultimately to improved outcomes for consumers.

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