



SUBMISSION TO THE ACT GOVERNMENT

**REVIEW OF THE *MENTAL HEALTH*
(TREATMENT AND CARE)
*ACT 1994 (ACT)***

**Incorporating outcomes from the MENTAL HEALTH
CARER CONSULTATIONS on 28 August 2012**

SEPTEMBER 2012

About Carers ACT

Carers ACT is the recognised and expert voice with and for Carers, as well as being the major provider of carer services and supports in the ACT. Carers ACT is a member of the National Network of Carers Associations. It is a non government, not for profit association that relies on public and private sector support to fulfill its mission with and on behalf of carers.

Carers ACT acknowledges that modern day Canberra has been built on the traditional lands of the Ngunnawal people. We pay our respects to their elders past, present and future, and celebrate the Ngunnawal people's living culture and valuable contribution to the ACT community.

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CARERS ACT SUBMISSION TO INFORM THE REVIEW OF THE MENTAL HEALTH (TREATMENT AND CARE) ACT 1994 (ACT)

Introduction

The *Mental Health (Treatment and Care) Act 1994 (ACT)* (hereafter 'the Act') is being reviewed to reflect the impact of significant changes to the legislative environment, clinical approaches and human rights principles.

Carers ACT is the peak body for carers in the ACT. It has a key role to play in ensuring that the perspectives and experiences of Canberrans who care for people with mental health support needs are considered and included in the legislative reform process.

Mental health is a policy priority for Carers ACT in the 2012 ACT election campaign and has been included as a strategic priority for Carers ACT over the next three years.

To afford mental health carers an opportunity to provide input to the review, Carers ACT hosted a consultation forum on 28 August 2012. Representatives of the legislative review team attended to provide further information and to respond to requests for clarification.

The second exposure draft of the revised legislation is anticipated to be released in December 2012, with passage expected towards the end of 2013. As such, Carers ACT is submitting this response to the ACT Health Directorate with the expectation that it will inform the second exposure draft. This submission incorporates the outcomes from the consultation forum, as well as input from Carers ACT based upon evidence provided to Carers ACT by mental health carers through consultations over many years.

The structure of this submission is as follows:

- Part One grounds the submission in the current thinking about carer and consumer rights, including consideration of the wider legislative and policy framework;
- Part Two turns to specific areas of consideration in the Draft Bill;
- Part Three examines the recognition of carer principles in other jurisdictions; and
- Part Four outlines recommendations and conclusions.

PART ONE: Understanding the Issues

The wider reform context

Many carers of people with mental health issues who attended our forum believe that the existing legislative framework for the care and treatment of people with a mental illness is flawed and out-dated. Legislative reform is welcomed but must be done in a holistic manner, capturing the breadth of issues across government organisations, other stakeholders, rights, responsibilities, policies and practices.

Reform to the Act is also necessitated by developments internationally and nationally, as well as at the state and territory level. At the international level, significant developments include the *United Nations Principles for the Protection of Persons with Mental Illness and for the Improvement of*

*Mental Health Care*¹ and the *United Nations Convention on the Rights of Persons with Disabilities*.² This latter instrument contains protection of the individual's right to "autonomy including the freedom to make one's own choice."³

Other significant changes driving the need for reform in legislation in the area of mental health include the development of the *Human Rights Act 2004* (ACT) and associated principles as expressed in the *ACT Charter of Rights for People who experience Mental Health Issues* (2011).⁴

So how do carers fit into these developments?

Carers ACT believes that the developments referred to above are in the best interests of people with a mental illness as well as the people who care for them. Consumer rights and the wider human rights discourse form an important protective mechanism against abuse, recognising and giving effect to the intrinsic dignity, humanity and capacity of people with a mental illness.

In amending the Act however, those drafting the Act should be aware that the patient/consumer rights based approach forms only a partial solution towards the fulfilment of a true recovery based approach to mental illness:

Civil rights generally are constituted as defences erected around individual actors. They allow individuals to vouchsafe a space into which others will not trespass. The rights focus, therefore, tends to emphasise **peoples' separateness**. It places a relatively lower premium on the **desire of others to assist** [emphasis added].⁵

It is this consideration – the 'desire' (or oftentimes, the necessity) of people to assist – the role of unpaid carers is important to the full obtainment of right and recovery for people with a mental illness. This is because many carers help provide the supportive home environment, the social networks of friends and family and the everyday support (including financial support) and care necessary to give full effect to recovery. Without considering the role of carers, the welfare and wellbeing of the consumer is only being addressed partway. Therefore, recognising carers also recognises the realities and the lived context of many people with a mental illness.

The inclusion of carers as partners in care is reflected in existing legislative instruments, with the *Carer Recognition Act 2010* (Cth) recognising the essential role played by carers in providing support during periods of both treatment and wellness for people with a mental illness. Similarly, Standard 7 of the *National Standards for Mental Health Services 2010* focuses on the central involvement and rights of carers in delivery of mental health services, including:

¹ *Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care*, United Nations General Assembly (1991) 46th Session, Item No. 98(b).

² *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 993 UNTS 3 (entered into force 3 May 2008).

³ *Ibid* art 3(a).

⁴ Note, the Charter is not law, nor is it directly enforceable in a court or tribunal. However, as the ACT now operates under the *Human Rights Act 2004* (ACT), "public authorities have an obligation to act in a way that is consistent with human rights protected by that Act and to consider those human rights in decision-making" – from ACT Government, "Community engagement feedback report on the public consultation for the Draft ACT Charter of Rights for Mental Health Consumers" (2011).

⁵ *Ibid*.

- 7.2 The MHS [Mental Health Service] implements and maintains ongoing engagement with carers as **partners** in the delivery of care as soon as possible in all episodes of care.
- 7.3 In circumstances where a consumer refuses to nominate their carer(s), the MHS reviews this status at regular intervals during the episode of care in accordance with Commonwealth and state / territory jurisdictional and legislative requirements
- 7.7 The MHS has documented policies and procedures for clinical practice in accordance with Commonwealth, state / territory privacy legislation and guidelines that address the issue of sharing confidential information with carers.
- 7.10 The MHS actively seeks information from carers in relation to the consumer's condition during assessment, treatment and ongoing care and records that information in the consumer's health record.
- 7.12 The MHS engages carers in discharge planning involving crisis management and continuing care prior to discharge from all episodes of care.⁶

PART TWO: Consideration of Provisions in the Bill

This section considers particular aspects of the Draft Bill under thematic headings. This approach was chosen given that in progressing the Bill towards passage, there will be significant reform and alteration in the content of the amendments. Consequently, an approach that too specifically considers each provision would not be an effective way of informing the submission procedure. Each section is followed by a list of recommendations that are also included in the recommendations section to this submission.

The areas discussed in this section are:

- Recognition in the proposed amendments
- Privacy and inclusion in balance
- Advance agreements
- Forensic Mental Health Orders
- Risk Assessments- the 'Safety Valve'
- Paramedics Power to Apprehend
- Assessments.

Recognition of carers in the proposed amendments

In light of the developments outlined above, Carers ACT had hoped that the new Act would be informed and directed by the increased recognition of carers at the national, and state and levels. We are disappointed to see that in the text of the Draft Bill only two direct references are made to carers – in s53D(d) which refers to carers within the context of advance agreements, and in s139B(2)(a)(ii), with reference to the role of a carer representative on the membership of the Mental Health Advisory Council. While this recognition is welcomed, Carers ACT seeks greater acknowledgement and inclusion of carers in the proposed amendments, especially as the *Summary of Proposed Changes* states that the Bill is: “a major piece of legislation which can have a significant impact on the lives of people with mental illness or dysfunction, their families and carers.”

⁶ Australian Government Department of Health and Ageing, *National standards of Mental Health Services* (2010). Available at: <http://www.health.gov.au/internet/main/publishing.nsf/content/mental-pubs-n-servst10>; emphasis added.

Recommendation: *That the ACT Government includes increased recognition of the rights and the role of carers in promoting the recovery of people with a mental illness in the Act, paying particular attention to this recognition as outlined in Commonwealth and Territory legislation and frameworks, such as the Carer Recognition Act 2010 (Cth) and the National Standards for Mental Health Services 2010.*

Privacy and Inclusion in Balance

Carers ACT is aware of the tensions that can arise when considering the consumer's right to choice and control over individual treatment decisions, and the role of carers in that individual's life. However, such an exercise should not necessarily be characterised as a conflict between two competing perspectives. Rather as discussed above, Carers ACT contends that in order to give full effect to the rights of mental health consumers, it is also important to support carers in their caring role.

This nuanced perspective is not currently reflected in the Act – or in the proposed amendments. Indeed, many carers have indicated to us that they consider the current system can be a barrier to successful treatment and care. For example:

I have a son who has a mental illness. He has also been treated for cancer. When he was being treated for cancer, I was welcomed in to treatment discussions, kept informed by medical practitioners and supported in every way to participate in the management of my son's care. When seeking the same response to his mental health crisis, every door was closed to me in the name of protecting his privacy.

Mental Health Carer

While Carers ACT agrees that the rights of all individuals to privacy and agency is a fundamental human right, a risk-averse application of privacy and confidentiality principles can sometimes lead to poor outcomes for carers and the people they care for.

This occurs in situations where an inflexible focus to protection of privacy means that carers are excluded from treatment planning, discharge and transfer information, but are still expected to manage the day-to-day care when the person returns to the home environment or the care situation.

This narrow approach to privacy minimises and excludes the important contribution that carers can make to informing the treatment planning process – especially given that they are often 'experts in care' – including when the person with a mental illness is unwell and thus unable to exercise full or limited decision-making capacity.

The following story indicates some of the difficulties presented by the application of a narrow approach to privacy:

My daughter was going through a bad period and had delusions that I was trying to harm her. Because of this, I was not consulted by any of her treating physicians even though I have lived with her and cared for her every day for the last 20 years. She was in no state to be able to advise the doctors, but I was deliberately excluded.

Mental Health Carer

Situations like this occur despite legislative instruments like the *Health Records (Privacy and Access) Act 1997* (ACT) explicitly stating that in cases where the consumer lacks capacity, the clinician can disclose relevant information necessary for the “carer to safely and effectively provide appropriate services to, or care for, the consumer.”⁷

As the story above illustrates, the translation of these provisions into policy and practice appears to be lacking. Consequently, there is a clear need for plain-English provisions within the amendments to the Act that stress the importance of the involvement of carers in treatment decisions and disclosure of treatment information.

Potential ways of including such recognition are discussed in greater detail in the recommendations section below, and in relation to other legislative instruments from NSW and Scotland.

Recommendation: *That the ACT Government includes the provision for carers to access important information regarding the treatment, detention, discharge and transfer of the person being cared for in the Act.*

Advance Agreements

Carers ACT supports the focus on consumer capacity, agency and human rights as outlined in the proposed amendments. Of particular interest is the inclusion of advance agreements in the Act. This is a promising development; one which will hopefully give greater weight to the wishes of consumers in the treatment process – and where the consumer elects to do so the inclusion of carers as ‘partners in care.’

While the legal weight of such agreements is fairly minimal, Carers ACT believes the real value of advance agreements is as an important starting point for meaningful and inclusive discourse between professionals, consumers and carers about treatment and recovery.

Evidence from research and other jurisdictions indicates a low-uptake of advance agreements in contexts where there is little or no public education campaign. For instance, in the United States, research has shown that “consumers are slow to take advantage of advance directive options but have a strong and consistent commitment to their use.”⁸ Some of the barriers to their use include “lack of ready access to them in a crisis, a lack of clinician familiarity, and legal uncertainty about their application.”⁹

Similarly many mental health carers at our consultation forum held in August 2012 were not aware of the current advance agreement process and the options that they have to participate. There also appears to be confusion about:

- whether an advance agreement is the same as an advance care plan
- whether an advance agreement can be negated or overridden by another agency or other legislation
- the difference between an advance agreement and a care plan.

⁷ Principle 10, Clause 4.

⁸ Penny Weller, *Advance Directives and the translation of human rights principles in mental health law- towards a contextual analysis* (Quarterly Mental Health Consumer, Carer and Community Forum, Mental Health Community Coalition ACT, May 12 2008) 13.

⁹ Ibid.

In addition, a carer sought clarification on s.52G, whether people must have decision-making capacity before they can terminate their advance agreements.

Subsequent to the consultation forum held in August 2012, Carers ACT received a suggestion from a carer recommending that the advance agreement be developed similarly to an aged care or disability care plan. In this model the family and carer and the service provider would be involved with the person with a mental illness to develop an advance agreement that sought to achieve quality of life and outcomes for the person with a mental illness.

In response to the range of comments received from carers, Carers ACT believes that raising awareness of this important tool is a key ACT Government action in conjunction with the ACT mental health sector to inform the implementation of revised legislation, in particular, advance agreements.

Recommendation: *That the ACT Government provides awareness of, and education on, the role of advance agreements to consumers and carers in conjunction with mental health organisations so that there is a proper utilisation and uptake of this important tool.*

Forensic Mental Health Orders

Carers ACT wishes to clarify the potential inclusion of carers within the following provision within the forensic orders section (Chapter 6):

- s48Z(d) states that the (ACAT) must take into account, “the views and wishes of the people responsible for the **day-to-day care of the person**, to the extent that those views and wishes **are made known to the ACAT**” [emphasis added].

The potential application of this provision to carers is not clear. This is for several reasons. First, the meaning of ‘day-to-day care’ is ambiguous, and could refer to paid as well as unpaid carers. Second, if it is intended for the section to refer to unpaid family carers, then such intention should be made explicit; this will assist carers to engage with, and understand their rights within the Act. Third, the phrase “to the extent that those views and wishes are made known to ACAT” seems to place an onus on carers to present their views and wishes to ACAT, rather than ACAT having a responsibility to inquire into the family and care situation of the person that they are making a determination about.

Another concern is if s48Z(d) is taken to be a carer-inclusive section, it is unclear why this approach is not followed in s48Y. While this section requires ACAT to consult with parents (if the person is a child), guardians, the person’s attorney, ‘nominated persons’, the person providing the treatment to be ordered, and the director-general under the *Corrections Management Act 2007* (ACT), no mention is made of the primary carer. Clearly carers could be captured under a number of these different categories; however Carers ACT believes it is of great importance to have a further, explicit reference to carers. Such a section would capture the diversity of carers and ensure that ACAT is accessing all opinions and views necessary to making the most appropriate decision.

Recommendation: *That the ACT Government provides clear definitions of carers (unpaid family or primary carers) in the Act to ensure that carers are adequately included in determinations of*

forensic mental health orders by ACAT, including the addition of a direct reference to unpaid carers in s48Y.

‘Safety Valve’ Provisions

Carers ACT supports moves towards a capacity-based approach to mental health. Such moves reflect best practice, our international legal obligations, and the human rights framework within the ACT. However, in situations where people with a mental illness present a real risk of harm to themselves, their carer and family, or the community at large, Carers ACT supports the inclusion of the so-called “safety valve” provision in the draft amendments. This provision means that even in cases where the person is found to have capacity to make decisions, they can still be placed on an involuntary treatment order. While such orders are clearly not ideal, it is necessary in cases where protection from harm is required.

On the issue of the ‘safety valve’ protection, Carers ACT would like more information about the following statement in the *Draft Explanatory Statement*:

Risk criteria are retained in the revised Act, so that if a person is assessed as having capacity, but there is still considered to be a clear overriding risk of harm to self or others, the person may be placed on an involuntary order. It is considered that such circumstances would be rare, **but at the time of drafting the new law, no jurisdiction in Australia or internationally has moved to ‘pure’ capacity based legislation and it was not considered reasonable for the ACT, as a small jurisdiction, to bear to risk of being the first to make this change.** The criteria for involuntary orders will be reviewed after 3 years [emphasis added].¹⁰

This statement raises many questions. First of these is whether is it envisioned that in the future there will be moves towards a ‘pure’ capacity based system in the ACT? This appears to be suggested in the wording of this statement. Second, how would such a system function, and what, if any, protective mechanisms would exist in the case of a person with capacity who poses a risk of harm to themselves and/or others?

Recommendation: *That the ACT Government clarifies what is meant by a ‘pure’ capacity based system in the Draft Explanatory Statement, and whether it is intended that the ACT should develop such an approach in the future.*

Paramedics Power to Apprehend

Carers ACT and carers at the forum welcome the extension of powers to apprehend to include paramedics with 15 years experience or more. Many carers consider the detrimental impact on individuals with a mental illness arising from police involvement in the apprehension process to be a contributor to feelings of persecution and high anxiety on the part of the individual as well as feeding the stigma which exists in the community regarding people with mental health issues.

The stigma of being taken away by the police is extremely detrimental to people with mental health issues and the people who live with them. Neighbours see the police car in the driveway and assume the worst. An ambulance is likely to be better perceived by the individual and those around him/her.

Mental Health Carer

On the issue of paramedic apprehension powers, there are a few issues of concern that Carers ACT would like to see clarified. These issues include:

¹⁰ *Draft Explanatory Statement* page 4.

- Practical concerns: the amendments relate only to paramedics with 15 years' experience or more. Carers ACT is concerned that this may limit the pool of trained or experienced staff available to respond in a timely manner to a critical incident.
- Issues of training: We query the arbitrariness of the 15 years experience test on the grounds that it does not necessarily translate into an ability to effectively undertake apprehension responsibilities – particularly as this is a new role for paramedics. Therefore this provision should ensure that staff with apprehension powers must undertake a training course to ensure that they can undertake this new responsibility effectively and safely.
- Working collaboratively with paramedics: Carers ACT believes that before paramedics take on this new role, they must be provided with appropriate tools. In a South Australian study of paramedics who had responded to mental health incidents, it was found that paramedics were often concerned about their safety, and that they wanted more information and training on how to respond appropriately to such calls.¹¹

Recommendation: *That the ACT Government in the implementation of the Power to Apprehend policy:*

- *Considers the necessity of the 15 years experience rule and its impact on the pool of trained or experienced staff available to respond to an 'apprehend' situation*
- *Undertakes adequate consultation and training with paramedics to identify and implement best practice to apprehend*

Assessments

Carers ACT welcomes the inclusion in Chapter 3 (sections 9C-9R) of amendments clarifying and streamlining applications for assessment as they have the potential to improve and maintain relationships between carers and the people they care for. This is because carers would apply for an assessment, rather than an application for a Mental Health Order.

PART THREE: The inclusion of carers in New South Wales mental health legislation

In reference to potential ways of giving effect to the rights of carers as well as mental health consumers in mental health legislation, Carers ACT notes that the *Mental Health Act 2007* (NSW) makes explicit reference to carer rights. Chapter 4 – Care and Treatment – addresses the inclusion and information-sharing rights of carers in detention, transfer and treatment. Carers ACT believe that this legislation provides a model of how carer interests and rights can be included in the ACT's new Act as well as giving effect to consumer rights and recovery.

Examples of the NSW provisions include:

Section 73 Information about medication

(1) On a request made under this section, an authorised medical officer of a mental health facility must provide particulars of the types of medication and dosages of each type of medication currently being administered or recently administered to a patient or person detained in the facility.

(2) A request may be made by:

(a) the patient or person detained in the mental health facility, or

¹¹ Louise Roberts, Julie Henderson, "Paramedic perceptions of their role, education, training and working relationships when attending cases of mental illness" 7 (2009) *Journal of Emergency Primary Health Care*.

- (b) the **primary carer** of any such patient or person, or
- (c) a representative of any such patient or person at a mental health inquiry or before the Tribunal.

Section 78 Notifications to primary carer of events affecting patients or detained persons

- (1) An authorised medical officer of a mental health facility must take all reasonably practicable steps to notify the **primary carer** of a patient or person detained in the facility if any of the following events occurs:
- (a) the patient or person is absent from the facility without permission or fails to return at the end of a period of leave,
 - (b) it is proposed to transfer the patient or person, or the patient or person is transferred, to another mental health facility or other facility,
 - (c) the patient or person is discharged from the mental health facility,
 - (d) the patient or person is re-classified as a voluntary patient,
 - (e) it is proposed to apply to the Tribunal for an ECT inquiry under Part 2 or to ascertain whether the patient or person is capable of giving informed consent to electro convulsive therapy,
 - (f) a surgical operation is performed on the patient or person under Part 3,
 - (g) it is proposed to apply to the Director-General or the Tribunal for consent to a surgical operation or special medical treatment under Part 3.
- (2) The authorised medical officer must give the notice as soon as practicable after becoming aware that the event has occurred.
- (3) In the case of a proposed transfer, the notice must be given before the relevant order or arrangement is made, except in an emergency.

PART FOUR: Conclusion and Recommendations

Conclusion

The Carers ACT submission on the amendment of the *Mental Health (Treatment and Care) Act 1994* (ACT) is based on consultations with carers, and current developments in mental health and carer recognition. In doing so, Carers ACT has acknowledged the complexity of the issues involved in this topic, and has offered a perspective on recovery and consumer rights that views carer involvement and consultation as central to giving greater effect to consumer wellbeing.

The key recommendations of this submission are outlined below.

Recommendations

Based on consultation with Canberrans who care for people with mental health support needs, our long history of engagement with carers, and our reading of the proposed Bill in light of key developments in policy and research, Carers ACT has identified the following as being of principal importance in progressing the review of the *Mental Health (Treatment and Care) Act 1994* (ACT).

Carers ACT recommends that the ACT Government:

- 1.** *Includes increased recognition of the rights and the role of carers in promoting the recovery of people with a mental illness in the Act, paying particular attention to this recognition as outlined in Commonwealth and Territory legislation and frameworks, such as the Carer Recognition Act 2010 (Cth) and the National Standards for Mental Health Services 2010.*
- 2.** *Includes in the Act the provision for carers to access important information regarding the treatment, detention, discharge and transfer of the person being cared for.*
- 3.** *Provides awareness of, and education on, the role of advance agreements to consumers and carers in conjunction with mental health organisations so that there is a proper utilisation and uptake of this important tool.*

4. *Provides clear definitions of carers or (unpaid family or primary carers) in the Act, to ensure that carers are adequately included in determinations of forensic mental health orders by ACAT, including the addition of a direct reference to unpaid carers in s48Y.*
5. *Clarifies what is meant by a 'pure' capacity based system in the Draft Explanatory Statement, and whether it is intended that the ACT should develop such an approach in the future.*
6. *In the implementation of the Power to Apprehend policy:*
 - a. *considers the necessity of the 15 years experience rule and its impact on the pool of trained or experienced staff available to respond to an 'apprehend' situation*
 - b. *undertakes adequate consultation and training with paramedics to identify and implement best practice to apprehend.*