



**Response to the Options Paper: Review
of the Australian Capital Territory Mental
Health (Treatment and Care) Act 1994**

**A Submission to Aequitas Consulting and the
Mental Health Policy Unit of ACT Health**

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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 and recognize the displacement and disadvantage they have suffered since European settlement. Carers ACT celebrates the Ngunnawal's living culture and valuable contribution to the ACT community.

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This document is a response to the Options Paper: Review of the Australian Capital Territory *Mental Health (Treatment and Care) Act 1994* which is accessible at <http://www.health.act.gov.au/c/health?a=sp&pid=1155860255> on the ACT Health website.

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1. Executive Summary

Carers ACT is a non-profit, community based, incorporated association and registered charity dedicated to improving the lives of all Carers living in the Australian Capital Territory. Carers are people who provide informal and unpaid care to a family member, a neighbour or a friend. They may be caring for someone with a disability, a mental illness, a chronic condition, someone who is aged and frail, or who needs palliative care.

The well-being and health of their loved one is a paramount concern for all Carers. The provision of ongoing care and support by Carers has a proven impact on assisting the process of recovery and the prevention of relapse for Consumers. Yet, the complexity of caring for someone with mental health issues while also dealing with 'the system' creates additional challenges for many Carers.

This submission highlights several systemic barriers faced by Carers when trying to ensure the effective care and treatment of their family member, partner or friend in the ACT. The removal of many of these barriers depends upon legislating for the creation of an inclusive system of treatment, enabling the effective and equitable contribution of Consumer, Carer and health professional; similar to other legislative reforms already undertaken elsewhere within Australia. It is essential that:

- The needs and perspectives of Consumers and Carers are not assumed to be homogenous;
- Each retains the right to make choices about their own health and wellbeing, and to access effective supports when needed;
- Revision of the Act balances the human rights of Carers with those of Consumers, achieving an equity which is respectful of each individual's needs.

It is vital that the revised legislation reflects the contemporary reality of community care, and recognises the rights of Consumers and Carers to be consulted and actively involved at every level. The ACT Government needs to commit to:

- Reviewing and revising all policies relating to mental health;
- Building a responsive and inclusive system appropriately supported by sufficient funding;
- Incorporating a comprehensive education program on rights and responsibilities under new legislation; for service providers, health professionals, Carers and Consumers.

Carers ACT considers that a revised Act would benefit from the inclusion of a comprehensive statement of principle reflecting an over-arching human rights focus for both Consumers and Carers. This principle needs to be supported by a definitive list of objectives:

- Carer recognition in their own right as a provider of care, not simply as just an advocate for the Consumer;
- Carers consultation on all aspects of care and treatment which will directly affect them in their caring role, unless there are compelling reasons for them not to be consulted;
- Achieve balance between individual rights to privacy and the need for appropriate communication of essential information to ensure proper care and treatment;

- Carer right to request confidentiality regarding information disclosed to a treating health professional, especially regarding their caring role and personal needs;
- An extension of the duty of care of treating professionals beyond the Consumer to the Carer, as Carers provide the essential support that enables the community care model to exist;
- Development of risk management plans for families and Carers, for all community-based treatment and care plans.

Many of the following issues are subject to intensive and ongoing debate between Consumers, service providers and treating professionals. While Carers ACT acknowledges and respects the debate, this paper necessarily restricts its consideration to the impact of legislative change on issues for Carers only.

Mental Illness and Mental Dysfunction

- Any removal of provisions and principles related to people with intellectual disability or other cognitive dysfunction must not create a gap in the provision of their effective protection, care and treatment.

Advanced Care Directives

- Establishment of a separate section under the Act on the use of future care statements would be best detailed with explicit and comprehensive provisions related to status, development, use and review;
- Carers will be supplied with a copy of an Advanced Care Directive, where such a plan will directly or indirectly impact upon their provision of care;
- Requirement that treating professionals report reasons for their non-compliance with any advanced directives in writing. Copies of this report should be supplied to both the Consumer and the Carer on request.

Voluntary Treatment

- Strengthen the existing legislation to increase its focus on voluntary treatment, especially in regard to recognising that all relevant provisions need to be extended beyond acute care and into the community care domain;
- Refusal of a request for voluntary treatment to require a written statement from the service provider stating the reasons for refusal and to provide information on alternative options for care, treatment and/or assessment;
- Reporting on refusal of treatment to include a risk assessment for the Consumer and Carer.

Involuntary Assessment and Treatment

- Carer must be consulted in relation to judgements of competency or capacity, unless there are compelling reasons for such consultation not to be obtained;
- Reasons recorded in writing and made available to the Carer on request;
- Provisions for Carer input on compliance and reporting need to be ensured under a revised Act.

Care and Treatment

- Adoption of a system guided by the Western Australian model where policy directives are underpinned by definitive legislation in the provisions of the *Mental Health Act 1996* and the *Carers Recognition Act 2004* which requires compliance reporting.

Transport

- Provide for transport of mental health Consumers via ambulance services, to reduce unnecessary distress and anxiety to Carers and Consumers;
- Adoption of a Crisis Intervention Team response model, similar to that used by the Memphis Police Department.

Rights

- Provisions for consultation and information on rights. Also to include a pathway of appeal to an independent arbitrator if access or involvement is denied.

Mental Health Tribunal

- Proposed reforms to the Mental Health Tribunal need further development;
- Carers representatives to provide greater input into the operations of the Tribunal;
- Individual Carers need to receive sufficient information, advocacy support and recognition when involved in a tribunal hearing;
- Submission of a 'Carer Impact' statement at each hearing where a Carer is involved;
- Legislative recognition and protection is required for Young Carers who operate under a legal disability before reaching 18 years of age;
- Carers and Consumers to have an appropriate forum where they can address their concerns about care and treatment.

Forensics

- Removal of all forensics issues to a separate Act, to prevent the continued blurring of boundaries between mental illness and criminality, and prevent the justice system being used as a 'dumping ground' for people with mental health issues.

Children and Young People

- Recognise Young Carers as a significant, and often sole, provider of care for Consumers with mental illness;
- Comprehensive provisions under the Act addressing the needs of Young Carers aged under 18;
- Requirement that services have a defined policy framework that supports family-centred practice;
- Provision that the welfare of any child or young person involved as a Carer of a mental health Consumer is paramount and takes priority over any other competing interests.

Other Oversight Bodies

- Any or all oversight bodies created or continued under the revised legislation make provision for active participation and input, at the highest level, from Carers and from Consumers as to their terms of reference and ongoing operation.

2. Introduction

Carers ACT is a non-profit, community based, incorporated association and registered charity dedicated to improving the lives of all Carers living in the Australian Capital Territory. Our role is to work in active partnership with Carers, people with care and support needs, health professionals, service providers, government and the wider community to achieve better understanding and an improved quality of life for Carers.

Carers are people who provide informal and unpaid care to a family member, a neighbour or a friend. They may be caring for someone with a disability, a mental illness, a chronic condition, someone who is aged and frail, or who needs palliative care. Anyone can become a Carer, at any time, as we all have family, friends or neighbours who may need our care at some time in their lifespan. Therefore, decisions on current and future supports for Carers have the potential to reach out to every section of community life.

The well-being and health of their loved one is a paramount concern for all Carers. The provision of ongoing care and support by Carers has a proven impact on assisting the process of recovery and the prevention of relapse for Consumers. The complexity of caring for someone with mental health issues while also dealing with 'the system' creates additional challenges for many Carers. This submission will highlight several systemic barriers faced by Carers when trying to ensure the effective care and treatment of their family member, partner or friend in the ACT. The removal of many of these barriers depends upon the creation of an inclusive system of treatment that enables the effective and equitable contribution of Consumer, Carer and health professional; similar to other legislative reforms already undertaken in other states and territories within Australia. For example, the Northern Territory's *Mental Health and Related Services Act 1998* is considered to be model legislation for the way it balances the rights of the Consumer with the rights of the Carer in access to information, decisions about treatment and care, and discharge planning.

Carers ACT offers a number of specialist programs to support people caring for someone with a mental illness. The Mental Health Respite Coordinator assists Carers to access respite options that are tailored for individual needs. The 'Keeping Families Connected' education course enhances existing skills to enable a better understanding of mental health issues. Peer support workers, with direct experience in caring for someone with a mental illness, are available to assist Carers in the psychiatric services units at Calvary Hospital and The Canberra Hospital. Carers ACT also offers a range of other services to benefit all Carers, including advocacy support and counselling services. It remains clear that there is more demand than can be met by existing funding available for services in the ACT. Carers ACT strongly supports the allocation of sufficient and recurrent funding to enable the better delivery of mental health support services to Consumers and to Carers.

It is critical that the needs and perspectives of Consumers and Carers are not assumed to be homogenous. Indeed, sometimes viewpoints and needs may be completely oppositional. Consumers retain the primary right to make their own decisions when well, and this may include a decision not to involve their Carers in a particular aspect of care. This right is recognised and respected by Carers ACT, as is the right for Carers to make choices about their own health and wellbeing, and about the supports they need to enable them in the continuation of care. To put it simply, the human rights of Carers need to be considered alongside those of

Consumers, achieving a point of balance and equity which is respectful of each individual's needs.

Carers ACT welcomes the ACT Government's commitment to legislative reform with an aim of protecting the human rights of people with mental illness and those who care for them. It is vital that the revised legislation reflects the contemporary reality of community care, and recognises the rights of Consumers and Carers to be consulted and actively involved at every level, from systemic policy or service planning to the development of individual plans for treatment or ongoing care. This submission will outline some key areas of concern for Carers, and make recommendations on ways to improve proposed revisions to the legislation.

Legislation is a critical component of social structure. It provides a foundation of support which underpins policy development and service provision. It outlines the rights and responsibilities of all people affected by the Act, and it ensures their due protection under the law. Reviews of legislation often draw responses from the wider community which are more about issues of policy or service delivery, but these issues often highlight areas where legislative direction is needed. Due to the complexity of the mental health arena, it is vital that the voices of Carers and Consumers are heard and considered to enable the construction of a better foundation based on just and equitable principles. The ACT Government needs to make a strong and unequivocal commitment to continue progress onwards from legislative reform by reviewing and revising all policies relating to mental health, with an aim to build a responsive and inclusive system appropriately supported by sufficient funding. As such, any revision of the Act will also need to be accompanied by a comprehensive education program on rights and responsibilities under the new legislation; for service providers, health professionals, Carers, and Consumers.

3. Principles and Objectives

a) Statement of principle

Carers ACT considers that a revised Act would benefit from the inclusion of a comprehensive statement of principle. This principle should reflect an over-arching human rights focus for both Consumers and Carers, and also incorporate words to the effect that:

Any person exercising any function of power under the Act is to ensure that this is done with regard for the protection of the dignity and self-respect of all parties directly concerned with or otherwise affected by the exercising of such powers.

b) Comprehensive objectives

The Act would be enhanced by the inclusion of additional objectives (improving on those currently in Part 2 of the existing Act) to enable a better reflection of current community values and practices, encompassing areas such as inclusive practice, prevention, and early intervention. The provision of clear and comprehensive objectives will also provide a set of core standards to guide the development and interpretation of all other relevant sections of the Act.

i. Recognition of Carers in their own right

It is very important that Carers are recognised within these objectives in their own right, rather than as a generic afterthought, tacked on with the usual

phrase of ‘... and Consumers and Carers’. While Consumers and Carers do often have common aims or goals, it is a frequent and dangerous misperception to assume that they are always working from the same perspective or have the same needs. In fact, sometimes their needs are competing, and it is vital that, in such circumstances, that a just and equitable balance be negotiated to ensure the best possible outcome is achieved for all parties. Carers are also far more than just an advocate for the Consumer, as they often have a central role in provision of emotional support and practical assistance, in addition to providing direct care and ongoing supervision of health and well-being. A clear understanding of this issue is essential to the development of workable mental health legislation.

ii. Right to consultation

A critical objective is the right for all Carers to be consulted on all aspects of care and treatment which will directly affect them in their caring role, unless there are compelling reasons for them to not be consulted. Any such reasons for not consulting Carers would need to be explicitly stated in writing and required to be kept on record. Carers ACT believes that inclusion of such an objective will clarify the expectations and define pathways for treating health professionals and service providers to interact with Carers in a more effective and cooperative manner.

Consultation greatly improves the accuracy of diagnosis and/or assessment of an individual’s condition. Nowhere is consultation more vital than in the area of mental health, where the Consumer may be completely unaware of any deterioration or may be wishing to hide their condition from the treating professional in fear of involuntary readmission.

Carers often disclose incidents, to staff at Carers ACT, where barriers to consultation have resulted in highly negative outcomes. For example: a Carer presented to a psychiatric treatment facility just after 5pm with a Consumer who was a previous attendee at the unit and who was in a highly distressed and suicidal state. The staff member in attendance at the unit refused to listen to the Carer’s pleas for emergency help, directing them to seek treatment through a hospital emergency department. The Carer was extremely fearful of the risk to the Consumer if they tried to move to another location. The refusal of the staff member to listen to the Carer’s concerns, to provide appropriate advice or to call for assistance, placed the Carer and the Consumer at significant risk of harm, and greatly intensified the trauma of the experience for both of them.

A clear requirement to consult under a revised Mental Health Act would clarify the responsibilities of all parties, and ensure that all relevant information is presented for consideration. If consultation was a matter of usual practice, this could be less threatening to Consumers when in situations of severe distress. Carers’ anxieties would be reduced by an assurance that they have a right to be heard, and that the expert knowledge gained from their caring role does not cease to exist whenever they walk in the door of a treatment facility.

iii. Right to provision of information

The provision of information to Carers is still a contested and misunderstood area. A balance must always be maintained between an individual’s right to privacy, and the need for appropriate communication of essential information

to ensure proper care and treatment. The revised legislation needs to contain clear directives as to when information can be provided, when it should be refused, and a requirement for documentation of any reasons for refusal. These objectives will clarify the expectations and pathways for treating health professionals and service providers to interact with Carers in a more effective and cooperative manner. Indeed, a continuation of the denial of information to Carers is actually a breach of their own human rights - as their dignity, personal wellbeing and safety may depend on knowledge of care and treatment issues which will directly affect them in their caring role. The structure of a community care model, which underlies all aspects of the health and social welfare systems in Australia, necessarily extends the duty of care of treating professionals beyond the Consumer to the Carer, providing the essential support that enables the model to exist.

For example, mental health staff working at Carers ACT report numerous occasions when Carers have been included in discharge plans for the Consumer, usually in a central role for assumed provision of care, but have been refused access to any information about the plan on the grounds of right to privacy. It is clearly unhelpful to the Consumer if the Carer arranges all of their transport and medication, but is not provided with key information about appointments, possible side-effects of new medications, and directions on circumstances when it may be appropriate to return for extra assistance. There is too much dependence on verbal information given to the Consumer, which may not be passed on to the Carer, and sometimes, due to the nature of the mental illness and the side-effects of medications, this information may not be clearly understood by the Consumer.

The dependence on verbal information can also be a problem for the Carer when in attendance at consultations. There may be language or cultural issues creating barriers to effective communication, or the Carer may be in a highly anxious or distressed state, particularly on occasions where an admission to acute care is required for the Consumer. The provision of written or other forms of information ensures that vital information is not missed, and can be reviewed later. It also assists with keeping accurate records for the Consumer's personal medical history. The provision of written information on the rights and responsibilities of the Carer under any revised Mental Health Act or other related act (such as the *Human Rights Commission Act 2005*) is also an essential part of effective service delivery.

It is not unusual for a Carer to visit a Consumer in hospital and find they have been discharged and are waiting to go home, with no more information than a couple of prescriptions and an appointment card. The inclusion of explicit standards of minimum written discharge information, provided to both the Consumer and the Carer, will enable communication pathways to be maintained. The provision of separate plans will also allow for privacy to be maintained, as confidential discharge information intended solely for the Consumer does not have to be printed on the Carer's version.

In Western Australia, the *Mental Health Act 1996* revisions require that clinicians routinely seek Consumer permission before disclosing information about the Consumer's condition or treatment to a Carer. However, section 206 contains an explicit list of circumstances where confidentiality may be breached. The Act, and supporting policies, also make it clear that even when Consumer permission is not given, Carers must be given "sufficient knowledge to enable them to provide effective care" (Department of Health,

2007, p. 11). This information may be specific in form or it may, as an absolute minimum, be general information about mental illness, detailing options for practical help and support. Sections relating to provision of information in the revised Western Australian legislation were modelled on similar provisions made in the Northern Territory *Mental Health and Related Services Act 1998* which is considered to be model legislation “as it includes provisions relating to Carer’s rights in relation to information, admission, treatment and discharge of the patient ... the Act made provision to balance the rights of both Carer and patient” (Carers Australia, 2007, p. 4).

Finally, Carers need to have the right to request confidentiality regarding information they may disclose to a treating health professional. Many Carers can feel highly conflicted when disclosing information about their loved one, especially if they know that the Consumer is reluctant to enter into treatment as a voluntary patient. They feel a primary loyalty to their loved one, and want to respect the wishes of the Consumer, but they fear the consequences for the Consumer if sufficient and appropriate help is not obtained.

Carers may also need to share information about their own caring role and personal needs to help the treating professional make informed decisions regarding options for care. For example, a Carer presents at a psychiatric unit with her son who has episodic incidents due to mental illness. The Carer speaks confidentially about her need for extra support and the impact of Caring on her health, as she has been diagnosed with a chronic condition requiring regular hospitalisation in the future. The Carer expresses a strong wish to continue caring for her son and a desire not to increase her son’s anxiety levels at this stage. The treating professional discloses the information when in consultation with the Consumer. The Carer feels personally compromised and is highly distressed, as she now has to cope with her son’s increased anxiety and the fact that he now tries to hide his symptoms. In all cases the Carer needs to be able to freely disclose their concerns or worries to the treating team without the fear of creating conflict with their loved one if sensitive information is disclosed.

iv. Right to safety

The amended legislation also needs to include a definitive objective stating that all assessment, treatment and care, whether in an acute care or community care setting, must address the risk of potential harm to families and Carers. The inclusion of this objective is to reflect the responsibility that treating professionals and services have an unambiguous duty of care to firstly ‘do no harm’ to the Consumer, but also that responsibility for their actions and decisions extends beyond the parameters of a ward or hospital bed, effectively extending their formal duty of care to the family and the Carer.

4. Definitions of Mental Illness and Mental Dysfunction

a) Revision of definitions

The definitions of mental illness and mental dysfunction contained in the existing Act are considered to be satisfactory, as they seem to be quite comprehensive in coverage. Carers involved in our mental health support programs have not raised any particular concerns regarding the existing definitions.

However, Carers ACT would also support a broader definition of mental illness, subject to reviewing final wording, as considered in options 2 & 4 in the Options Paper. Any alteration to these definitions would have to be carefully considered in light of the impact on other existing legislation, including the *Disability Services Act 1991*, the *Guardianship and Management of Property Act 1991*, the *Children and Young People Act 1999*, and the *ACT Carers Recognition Legislative Amendment Act 2006*.

b) Protection of individuals with mental dysfunction

It is vitally important that any removal of provisions and principles related to people with intellectual disability or other cognitive dysfunction does not create a gap in the provision of their effective protection, care and treatment. Removing a section of the population from the Act will not alter a genuine need for services where no other viable alternatives exist. Indeed, the main argument for removal of the category of mental dysfunction would seem to be based on issues of limited resources and a lack of suitable alternatives for care, rather than an issue of legislative inaccuracy.

Carers ACT absolutely upholds the need for the development of appropriate options and treatment facilities where people with intellectual disability and early dementia, for example, receive care that is not only available inside a locked ward facility designed for the specialist treatment of people with mental illness and at critical risk. The reality of competing resources also means that until such viable alternatives exist, the highly vulnerable section of the population who currently fall within the category of mental dysfunction will continue to need the legislative protection that enables the Territory's duty of care to be maintained.

5. Advanced Care Directives

There is consistent and widespread community support for the inclusion of Advanced Care Directives into revised legislation. Option 3 in the options paper is probably the most appropriate choice. A separate section under the Act on the use of future care statements would be best detailed with explicit and comprehensive provisions related to status, development, use and review.

Carers ACT proposes that this section of the Act also include a provision that Carers will be supplied with a copy of an Advanced Care Directive, where such a plan will directly or indirectly impact upon their provision of care. There also needs to be a requirement that treatment teams will need to report their compliance or non-compliance with the Advanced Care Directive, explicitly stating their reasons for any non-compliance in writing. Copies of this report should be supplied to both the Consumer and the Carer on request.

6. Voluntary Treatment

a) Response to requests for voluntary treatment

Carers ACT supports the option to strengthen the existing legislation to increase its focus on voluntary treatment, especially in regard to recognising that all relevant provisions need to be extended beyond acute care and into the community care domain. Carers ACT would also support the inclusion of a short section on the right to seek voluntary treatment. This section should detail all parameters of the rights and responsibilities of the Consumer, the Carer, and the treatment provider. This

section should contain a clear directive on the minimum requirements for assessment in response to a request for voluntary treatment.

b) Refusal to provide treatment

If a request for voluntary treatment is refused, the legislation should require the provision of a written statement from the service provider stating the reasons for refusal and providing information on alternative options for care, treatment and/or further assessment. This report should also include a risk assessment for the Consumer and Carer, i.e. a statement assessing the risk of harm based on current presentation and detailed written material on warning signs where additional help should be re-sought. This information is important as Consumers and Carers who are refused assistance may hesitate to recontact a service, even if the situation has further deteriorated, because they fear being sent away again. This statement should be supplied at the time of refusal of service to the Consumer, with a separate copy to be provided to the Carer.

7. Involuntary Assessment and Treatment

As previously addressed in the above sections, it is essential that Carers are provided with rights under this legislation that ensure their right to safety, their right to be consulted, and their right to any or all information that will directly or indirectly impact on their role as Carer.

In the area of involuntary assessment and treatment, it is vital that the legislation contain a clear directive that the Carer must be consulted in relation to judgements of competency or capacity, unless there are compelling reasons for such consultation not to be obtained, with these reasons recorded in writing and made available to the Carer on request.

Carers ACT supports an increase in provision for second opinions and/or assessments and the use of multidisciplinary panels in decision-making around involuntary orders. Greater public accountability on the use of restrictive powers and intrusive treatments is also welcomed. Carers ACT would welcome future planning on a mechanism for compliance and reporting to monitor an accountability process. It would be highly recommended that any such mechanism include Carer Representation on a review panel or committee, in addition to allowing pathways for Carer input into hearings or reviews of individual cases.

8. Care and Treatment

a) Principles underlying all care and treatment

Carers WA, in consultation with the Office of the Chief Psychiatrist of Western Australia, has developed a publication to facilitate a coordinated approach to care and treatment between health professionals, Consumers and Carers (see Appendix A for full document). The guide for health professionals, *Communicating with Carers and Families* (Department of Health, 2007, p. 5), sets out the following key principles for care and treatment:

- *Carers and families must be recognised, valued and supported in their care-giving role;*
- *Clearly defined roles and responsibilities for clinicians and Carers should be disseminated and understood by all;*

- *Carers and families should be consulted and engaged as soon as possible in any episode of care;*
- *Clinicians, Consumers, Carers and families need to communicate effectively and share information to ensure quality care;*
- *Clinicians must have a sound knowledge of what information may be given to Carers and families under different circumstances by referring to the relevant sections of Mental Health legislation;*
- *Services should ensure that the language and cultural needs of Carers are considered;*
- *Consumers' right to decide not to involve Carers should also be recognised and respected.*

These principles have been based on proven experience and research evidence which has consistently demonstrated:

- *That knowledge and information from family members and Carers can significantly assist towards making an accurate and informed assessment or diagnosis.*
- *That Carers and families can provide a wealth of information on the Consumer's history, health, behaviour and well-being at a time when the Consumer is often unable to convey such information.*
- *That treatment outcomes are improved by educating Carers about goals of treatment, the ongoing care needs of the Consumer and possible side-effects of any medications prescribed.*
- *That regular communication facilitates the early identification and attention to any issues that arise during treatment, and allows for effective care strategies to be developed in support of the Consumer both inside and outside of treatment facilities.*
- *That coordinated and cooperative liaison enables maximum opportunity for wellness, reducing the incidence of relapse.*
- *That engagement of Carers and families is cost-effective and has a positive benefit on outcomes.*
- *That timely and appropriate information and support to Carers helps to reduce the adverse impacts of caring on their own health and well-being.*

(Source: Department of Health, 2007, pp. 5-6)

The strength of the Western Australian system lies in the fact that policy directives are underpinned by definitive legislation in the provisions of the *Mental Health Act 1996* and the *Carers Recognition Act 2004*, which each require service compliance. The rights of the Consumer are respected and protected under these laws, and are appropriately balanced with the rights of the Carer to provide and receive information, and to participate equitably in the treatment and care process. The legislation also enables health professionals in both acute care and community care settings to have a clearly defined pathway of responsibilities and expectations to guide their role and actions in the delivery of treatment.

The existing ACT mental health legislation does not recognise Carers in their own right. There is no requirement for that plans for care include any consideration or assessment of the Carer's needs, treating professionals are not required to assess

the potential for impact or risk on the Carer, or provide them with information on support services that may be able to assist them to maintain their caring role. Effectively, the duty of care to the Carer implicit in the community care model of health and social welfare is not explicitly supported in the current legislation and neither is it explicitly excluded.

The ACT *Carers Recognition Legislation Amendment Act 2006* provided for amendment to the *Discrimination Act 1991*, the *Guardianship and Management of Property Act 1991*, and the *Human Rights Commission Act 2005* but these amendments are very limited in their scope. For example, being a Carer cannot be used in a discriminatory way for employment, accommodation, education, club membership, access to premises, or relating to goods, services and facilities. The *Discrimination Act 1991* does not apply outside of the ACT or in relation to any complaint against a Commonwealth Department or Agency. Under the *Human Rights Commission Act 2005*, Carers can make a complaint as an agent of the Consumer. There is no provision for services to recognise Carers in their own right, i.e. for them to complain on how they are treated by services. Under the *Guardianship and Management of Property Act 1991* all Carers must receive notification of a guardianship hearing. It is clear that increasing government and departmental recognition of Carers, the essential role of caring, and the enormous social and economic benefits to the community from caring must be underpinned by effective legislative recognition with definitive provisions on Carers rights and responsibilities.

b) Transport of individuals

Carers ACT unequivocally supports the planned revisions to provide for transport of mental health Consumers via ambulance services. The enforced use of police transport under the current legislation causes significant distress and anxiety to Carers, Consumers and families. It is a significant waste of police resources in the majority of cases when the Consumer is not a risk to themselves or to the community. It also serves to sustain the strength of current misperceptions in the wider community, associating mental health issues with criminality.

Carers ACT supports the provision of greater resourcing and training of police officers when responding to crisis situations involving a person with mental illness. The Crisis Intervention Team Program at the Memphis Police Department provides a best practice model for “community partnership working with mental health Consumers and their families” (Memphis PD, 2008). This model is proven in decreasing use of force, preventing injury and increasing positive outcomes for Consumers and Carers, it has also proved to be cost-effective.

9. Rights

Further to each of the rights previously discussed, the Options Paper proposes that the revised Mental Health legislation incorporate provisions similar to those used in the new Health Records Act. Carers ACT considers that all issues of confidentiality need to be explicitly addressed in any revised legislation, with definitive guidelines as to how and when information can be released. This provision needs to include a pathway of appeal to an independent arbitrator if access to information is denied.

Confidentiality needs are not a once-off, yes or no matter, as circumstances can vary significantly between stages of illness, the nature of information under consideration, and the context surrounding the disclosure. A definitive standard of professional ethics is needed to govern the process of communication with Carers and

Consumers during the delivery of service. As previously discussed, the Western Australian model allows for the appropriate communication of information “to others who are neither members of the healthcare team nor clinicians, such as family and Carers, to have access to certain information about the Consumer to help them make decisions in the best interests of the Consumer, and indeed themselves.” (Department of Health, 2007, p. 11).

10. Mental Health Tribunal

The Options Paper identifies a number of concerns and areas needing reform in relation to the operation and structure of the Mental Health Tribunal, but does not actually offer any definitive options or plan for a comprehensive restructure. It is clear that this area needs additional work. Whether the Tribunal remains a stand-alone body under the Mental Health Act, or it is absorbed into a new ‘super-tribunal’ system, the following statements apply in regard to Carers:

- a) Membership of the Tribunal needs to be more inclusive by extending participation to include a Carer representative in addition to current practicing psychiatric workers and Consumer representatives. Members need to be adequately compensated for their time.
- b) Provision to ensure Carers and Consumers are each given access to individual advocacy services during the Tribunal process, which will redress the often erroneous assumption that Carers and Consumers have homogenous needs and perspectives.
- c) Provision to require that Carers be given advance notice of any pending hearing of the Tribunal relating to their cared-for person. Sufficient notice for non-emergency hearings enable Carers to adequately prepare for the hearing and ensure appropriate supports are in place.
- d) Provision for the supply of a written document explaining the Tribunal process in plain English. This document would need to provide examples of likely outcomes, and detail clear pathways for additional support, and outline any appeal process (if such process is included in the revision). This document should be required to be given to all parties prior to commencement of a Tribunal hearing. Definitive guidance on the Tribunal process will greatly assist in reducing Carer stress and anxiety related to participation, and ensure that legal representation is only engaged when absolutely necessary, reducing unnecessary financial impact on Carers.
- e) Provision to allow for a statement of Carer Impact to be presented in all hearings and considered as part of the Tribunal’s deliberations. This provision to be supported by a written, plain English document explaining the terms of reference for the statement, and providing a pro forma for Carers to complete.
- f) Provision that ensures the establishment of specialist advocacy services for Young Carers, and where necessary, provision be made for separate legal representation to counter the legal disability faced by Young Carers.
- g) Extension of the role of the Tribunal, or establishment of a separate Mental Health Ombudsman or Commissioner, to ensure that Consumers and Carers have an appropriate forum where they can have their concerns about treatment and care issues addressed. This is especially needed in regard to Advanced Care Directives, compliance with provisions for fair treatment under the revised Act, and in relation to general standards of care.

11. Forensics

Carers ACT recognises the complexity of forensic issues currently addressed under the existing legislation, but strongly supports the removal of all forensics issues to a separate Act. The continued association of mental health issues alongside matters of criminality is a cultural artefact left over from the rise of the institutions for the 'criminally insane' in pre-Victorian England. No other legislation concerning general health and wellbeing, either within the ACT or in other states and territories, requires an inherent structure of forensic provision. The removal of all forensic issues to a separate act will greatly assist with removing stigma associated with mental illness in the general community.

It is vitally important that Consumers with mental health issues who are also involved in the justice system (referred to in the Options Paper as Forensic Consumers) are suitably provided for under revised legislation. The blurring of boundaries between mental illness and criminality continues to allow the justice system to be used as a 'dumping ground' for people with mental health issues who cannot be suitably accommodated and supported by treatment facilities within the ACT.

12. Children and Young People

The Options Paper refers only to children and young people as Consumers, and fails to address the children and young people who are Carers of people with a mental illness. Young Carers are those Carers under 25 years of age, who may be the children, the sibling or the partner of the Consumer. Carers ACT considers it essential that Young Carers are recognised under the revised Act as a significant provider of care for Consumers with mental illness. Young Carers need to be suitably protected by comprehensive provisions the Act, especially when aged under 18 and in a caring role.

Two new principles are needed under the revised Act, firstly, to encourage the maintenance of family relationships, and, secondly, to acknowledge that the welfare of any child or young person involved as a Carer of a mental health Consumer is paramount and takes priority over any other competing interests.

Provision also needs to be made for treatment facilities to be under obligation to have a defined policy framework that supports family-centred practice, including the development of adequately resourced family-friendly visiting areas, separate to the clinical environment, and an ongoing commitment to staff development in the area of family-friendly practice, as recommended by White (2007, COPMI commissioned report).

Young Carers operate under a legal disability. The revised Act will need to make provision for them to access support and advocacy services in their own right. The Act will also need to ensure that the rights awarded to other Carers in relation to information, consultation and outcomes planning, are extended to Young Carers. As discussed previously, they will also need to have the right to separate legal representation and support, in their own right as a Carer, when attending or otherwise involved in a Mental Health Tribunal.

13. *Other Oversight Bodies*

Carers ACT submits that any or all oversight bodies created or continued under the revised legislation make provision for active participation and input, at the highest level, from Carers and from Consumers as to their terms of reference and ongoing operation. The Office of the Public Advocate needs sufficient resourcing to attend all Mental Health Tribunal hearings, if requested by the Consumer or the Carer.

14. References

- Carers Australia (2007) *Inquiry into mental health services*. Canberra, ACT: Carers Australia reports and publications.
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- White, C. (2007) *Practical guidelines for promoting positive contact between children and their parents during their parent's psychiatric hospital admission*. Canberra, ACT: Children of Parents with Mental Illness (COPMI).

Appendix A

Reference: Health Department of WA (2007) *Communicating with Carers and families: Information sharing for better outcomes*. Perth, WA: Office of the Chief Psychiatrist, Health Department of Western Australia.

Communicating with Carers and Families

Information sharing for better outcomes

Information booklet and practice guide for mental health clinicians

The guide has been developed in partnership between the School of Psychiatry and Clinical Neuroscience, UWA; the Mental Health Division; the Office of the Chief Psychiatrist and Carers WA.

Introduction

Carers and families provide essential care and support for Consumers with mental health problems. Research demonstrates that better outcomes are achieved for Consumers, Carers and mental health clinicians by informing and engaging Carers early in the planning and on-going delivery of service. It is increasingly recognised that Carers play a critical role in the process of recovery and relapse prevention.

Current clinical practice should reflect the contribution provided by Carers. This includes optimising the engagement of Carers during service planning and delivery at multiple levels throughout mental health service organisations. Such engagement between clinicians and Carers must comply with the Western Australian Carers Charter mandated by the *Carers Recognition Act 2004*, which requires that Carers' different perspectives and need for information, skill development and support, be respected and recognised.

The term 'Carer' under the *Carers Recognition Act 2004* refers to a person nominated by the Consumer to provide care or assistance without payment apart from a pension, benefit or allowance to the Consumer because of the latter's frailty, disability, chronic illness, or mental illness. A Carer can be any Consumer-nominated friend, intimate, or housemate who provides essential ongoing care and support for that Consumer.

The issuing of this practice guide is consistent with the Chief Psychiatrist's statutory responsibility for the medical care and welfare of all involuntary patients, as well as for the monitoring of standards of psychiatric care provided throughout the state. This guide provides a general framework to guide good practice regarding issues of privacy, confidentiality and the sharing of information.

Key message

Effective communication with Carers is vital in the delivery of high quality mental health care. Carers must be recognised, respected, valued and supported for the essential service they provide. Where Consumers refuse to consent to the sharing of information, general information about mental illness can still be given to Carers without breaching confidentiality. Collaboration with Carers should be sought as early as possible in any episode of treatment and care.

Disclaimer

This guide is intended as general information and not as legal advice. This guide should not replace judicious professional judgement on each individual case. Whenever services consider it appropriate, legal advice should be sought and take precedence over this guide.

Purpose of the Guide

The purpose of this guide is to provide a framework from which to:

Develop procedural standards for clinical practice;

Consider ways to overcome difficulties associated with working with Carers;

Establish consistency of expectations and practice among mental health service clinicians working with Carers;

Clarify the legal and ethical provisions for confidentiality.

It is recommended that all mental health services across the public and private sectors develop policies and procedures for clinical practice that address the issues raised in this guide.

This guide aims to increase the knowledge and ability of staff to communicate effectively with Carers and families regarding issues of confidentiality.

Key service principles

Carers and families must be recognised, valued and supported in their care-giving role;

Clearly defined roles and responsibilities for clinicians and Carers should be disseminated and understood by all;

Carers and families should be consulted and engaged as soon as possible in any episode of care;

Clinicians, Consumers, Carers and families need to communicate effectively and share information to ensure quality care;

Clinicians must have a sound knowledge of what information may be given to Carers and families under different circumstances by referring to the relevant sections of Mental

Health legislation;

Services should ensure that the language and cultural needs of Carers are considered;

Consumers' right to decide not to involve Carers should also be recognised and respected.

Rationale

Research evidence consistently supports the benefits of working with Carers and families. Such benefits include:

1. Assessment

Knowledge provided by Carers and family members can facilitate making a diagnosis or assessment (e.g., a family history of schizophrenia).

2. Service delivery

Mental health Consumers are not always able to advocate competently for themselves, particularly in times of health crisis. Hence the Carer's perspective provides a critical, second source of information regarding the Consumer's health;

Carers and families often have an historical as well as intimate knowledge of the Consumer's health, behaviour and well-being that is not otherwise available to the treating clinicians. Such knowledge allows for regular feedback on changes in behaviour and the effects of a particular medication or treatment.

3. Treatment outcomes

Sharing information regarding the goals of treatment and care, including issues such as knowledge of side-effects of medication, educates Carers and family members as to what is needed for optimal ongoing daily care;

Regular discussions between mental health clinicians and Carers can ensure practical problems relating to day to day care are promptly identified and addressed. Problem solving skills can be taught and practiced to ensure effective care strategies.

4. Relapse admissions

Effective liaison between mental health clinicians and Carers will improve and maintain the quality of care provided for the Consumer at home to ensure maximum opportunity to wellness and reduce relapse rate.

5. Cost effectiveness

Evidence from research demonstrates that Carers and families are a vital resource in mental health services with their engagement in service delivery providing a highly cost effective method of improving treatment outcomes.

6. Carer support

International and Australian research evidence demonstrates significant, adverse impact of caring on the health and wellbeing of Carers and families. Timely and appropriate information and support can assist in reducing the adverse impact of caring.

Implications for mental health services and staff

Clinical practice standards, which promote an inclusive approach need to be established by all mental health services across the public and private sectors. Such an approach should promote Carers' strengths, acknowledge their difficulties, and help empower them in a practical sense to be capable and resourceful. Practice standards should particularly focus on enabling clinicians to work sensitively with Carers and families to build effective engagement.

It is vital that, with the permission of the Consumer, Carers are consulted and informed as early as possible; given timely, regularly up-dated information about mental illness, its likely course, treatment options and outcomes; and given feedback regarding clinical consultations and meetings.

The clinician's assessment of the family or Carer's ability to be involved will determine optimal, ongoing engagement.

The Consumer, Carer and family should be involved as much as possible in the development and regular updating of: a treatment and care plan; a crisis plan; a Carer list of contacts for access to support services.

Treatment plans

The views and preferences of the Carer and family should be taken into consideration in the development of the treatment plan. In relation to patients on Community Treatment Orders, all clinicians should ensure they are familiar with the provisions relating to treatment plans in section 68 of the Western Australia *Mental Health Act 1996*.

Carers or nominated support persons who have an agreed role in delivery of service or care are required under section 157 of the *Mental Health Act 1996* to be given an explanation regarding the rights and entitlements of the Consumer.

When Carers and family members are to be involved clinicians should ensure their needs (including cultural and language needs) are assessed at critical points, taken into account and addressed where possible.

If a Consumer refuses or limits the involvement of the Carer or family, the issue should be sensitively explored to identify the limits of the refusal.

Irrespective of whether or not the Consumer allows the wishes of the Carer to be taken into account, the Carer will still require: general information about mental illness; advice on problem solving, accessing practical help, responding to and coping with behaviours manifested by mental illness; general support including information about Carer support.

The role of the Carer and family providing support for the Consumer is a difficult one. The negative effect of the illness on the Carer and the associated reduction in their quality of life is significant. It is important for clinicians to recognise and address the reciprocal effect of the Consumer and Carer/family relationship by informing and supporting the Carer in addition to the Consumer.

Procedure and Documentation

Clear policy and procedural guides are required in all mental health services to enable staff to effectively implement and maintain Carer engagement in accord with the Western Australian *Carers Recognition Act 2004* and Carers Charter.

It is recommended that a consistent, structured approach be followed in regard to communicating with Consumers and Carers on issues of confidentiality; service documents should be used to record Consumer permission to verbally communicate information to the Carer, up to date Carer contact details, and the level of Carer engagement for which the Consumer has given permission; contact and discussions with Carers and families should be clearly documented in clinical records.

It is recommended that regular communication with Carers is maintained from intake throughout all stages of service delivery:

Intake

Carer contact details; Carer contacted, informed and given Carer support information.

Treatment plans

Consumer's permission requested to involve Carer in treatment plans; the extent of Carer involvement when only partial permission is given; any necessary follow-up.

Carer crisis plan

Indications suggesting Consumer's deterioration in health or impending crisis; suggested action the Carer can take to arrest deterioration; procedure and emergency contact details for Carer in times of crisis.

Referral, discharge and community treatment plans

Provision for maintaining Carer contact; regular update and review of information by treating clinicians.

The Ethics of Confidentiality

Professional ethics govern the communication with and engagement of Carers during service delivery. The codes of ethics and guides to professional practice that relate to the notion of confidentiality are summarised as follows:

The promise of confidentiality is a commitment that the patient's information will not be transmitted to a third party without the Consumer's express permission. The promise of confidentiality permits voluntary suspension of privacy when a person consults a doctor or other healthcare clinician on the understanding that his or her privacy will be maintained. The promise of confidentiality allows a person to reveal information about themselves, mind and body, in order that they can be assisted.

This promise is founded on the notion of respect for persons generally, respect for the right and capacity for self-determination, and as such is a principle that must be adhered to for its own sake. But this maintenance of privacy is also a requirement for a health system to function successfully in a community. People must be able to trust that health clinicians will keep their confidences secret so that they can effectively seek help. Hence, the goal of privacy is to optimise health outcomes for individuals in a community.

However, confidentiality is not absolute. Although a Consumer may voluntarily allow confidential information to be provided, the community, in the form of the state, may also mandate that a Consumer surrender the right to confidentiality if the community or individuals within the community are understood to be endangered.

The modern environment of healthcare provision is far more complex than the paradigm of a consultation between a single Consumer and a single healthcare clinician. In this context, it may be entirely appropriate for many members of a health care team to have access to sufficient information about a Consumer to facilitate that person's optimal care. In this context it may also be appropriate for others who are neither members of the healthcare team nor clinicians, such as family and Carers, to have access to certain information about the Consumer to help them make decisions in the best interests of the Consumer, and indeed, themselves. In such cases it may be appropriate for the clinicians to provide family and Carers with necessary information.

Policy Context

The third National Mental Health Plan 2003-2008 states that Carers and families are to be provided with improved support. Such support includes: providing Carers with information to promote their involvement in care; developing a Carer plan in conjunction with each Consumer treatment plan; regular review of each Carer's needs; ensuring a range of support services and resources are provided and accessible for Carers, including respite and assistance for children who have a parent with a mental illness.

Legislation

The disclosure of information by clinicians about Consumers of mental health services is governed by section 206 of the MHA. Clinicians must routinely seek a Consumer's permission before providing information about the Consumer's condition and treatment to a Carer. However, even when Consumer permission is not given, Carers are to be given sufficient knowledge to enable them to provide effective care. (See section 206 of the *Mental Health Act 1996* for the full list of circumstances in which mental health clinicians may breach confidentiality).

The Western Australia *Carers Recognition Act 2004* requires service providers to comply with the Western Australian Carers Charter, which states:

Carers must be treated with respect and dignity;

The role of Carers must be recognised by including Carers in the assessment, planning, delivery and review of services that impact on them and the role of Carers;

The views and needs of Carers must be taken into account along with the views, needs and best interests of people receiving care when decisions are made that impact on Carers and the role of Carers;

Complaints made by Carers in relation to services that impact on them and the role of Carers must be given due attention and consideration.

The decision by a Consumer not to permit or limit confidential information should be regularly reviewed. Carers are also to be given the opportunity to discuss and help in resolving difficulties involved in caring. Providing Carers with general information about mental illness, and practical and emotional support does not breach confidentiality.

Carer communication checklist¹

***ENLIST** Carers to build effective collaboration*

Engage: Carers are given general verbal and written information about:

The mental illness and diagnosis

What behaviour to expect and how to deal with it

Medication - alternatives, possible side effects and benefits

Planning to cope with care, signs of risk, crisis, and recovery

Other supports and information available for the Carer

Needs: Carers are cared for:

Ongoing opportunities to ask questions, give feedback, and discuss concerns

The opportunity to see a clinician on their own

The right to confidentiality in communications with a clinician

Positive feedback as a valued member of the care team

Available local services - both inpatient and community

Local and national support groups

Listen: Carers are encouraged to communicate:

Any history of the Consumer relevant to the mental health illness and diagnosis

Personal characteristics of the Consumer that may influence the choice of medication or treatment

Effects of medication or treatment on the Consumer

¹ This checklist is aligned with that provided for Carers' use in the Carers support information

Inform: Carers are given help in understanding:

The rights and responsibilities of Consumers, Carers, and mental health clinicians

Any restrictions on sharing information requested by the Consumer

The aims of, and what is involved in, the Consumer's treatment plan

The roles of each clinicians involved in care of the Consumer

Support: Carers are given advice:

Problems they have in caring for the Consumer and when they need help in practical problem solving

If they would like training in cognitive behavioural therapy

If they would like family therapy sessions

Confidence to express their opinion and concerns

Practical and emotional support

An assessment of their own needs and written care plan when required

Trust:

Trust is essential in good care. Trust must be developed between clinicians and Carers. The different problems faced by each need to be understood before mutual respect and helpful collaboration can grow.

Acknowledgement

Dr Hugh Cook's comprehensive 1996 Western Australian guide on *Confidentiality in mental health settings*, Professor C. D'Arcy Holman's *Review of the Mental Health Act 1996*, and the Chief Psychiatrist of Victoria Associate Professor Amgad Tanaghow's guide *Working together with Carers and families*, are gratefully acknowledged for their contribution to this guide.

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The information in this Guide will be reviewed periodically and amended as required.