



Submission to the

Review of the Mental Health Act 1990
Discussion Paper 1:
Carers and Information Sharing

April 2004

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WHO WE ARE

ACON (AIDS Council of NSW Inc.) is a health promotion organisation based in the gay, lesbian, bisexual and transgender communities with a central focus on HIV/AIDS. We provide HIV prevention, health promotion, advocacy, care and support services to members of those communities including Indigenous people, people who inject drugs, sex workers and all people living with HIV/AIDS. ACON has offices in Sydney, Western Sydney, Illawarra, Northern Rivers, Hunter and Mid North Coast with an extensive range of outreach services. ACON is also home to the Community Support Network (CSN), the Positive Living Centre (PLC), the Lesbian and Gay Anti-Violence Project (AVP) and the Sex Workers' Outreach Project (SWOP).

WHAT WE SEEK – OUR VISION

- A strong, healthy and resilient gay, lesbian, bisexual and transgender community.
- The health needs of our communities to be effectively addressed through all life stages.
- An end to the HIV/AIDS epidemic.
- A society that respects the basic link between health and social justice.

WHAT WE DO – OUR MISSION

- Drawing our strength from a dynamic relationship with our communities, ACON plays a leading role in promoting health.
- We do this through education, advocacy, and service provision and in partnership with researchers, health care providers, governments, our community members and others.
- HIV/AIDS is a key priority for our organisation.

WHAT WE BELIEVE IN – OUR VALUES

We believe the following are intrinsic to ACON and everything we do;

- Social Justice
- Partnership
- Equity and access
- The centrality to any health response of those affected
- Professionalism, accountability and quality
- Creativity and innovation
- Inclusiveness, respect and self-determination
- Community based
- Sustainability

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BACKGROUND

We are pleased to submit our views on the discussion paper 'Carers and information sharing', Review of the Mental Health Act 1990. This response has been developed drawing upon nearly twenty years experience in the provision of services to people living with HIV/AIDS an increasing number of whom are presenting with organic, psychological and psychosocial mental health conditions¹.

ACON provides a range of mental health clinical and support services for people living with HIV/AIDS and gay, lesbian, bisexual and transgender people with a diagnosed mental health condition. Services include short term solution focussed counselling, assessment and referral to mainstream mental health services and enhanced primary care coordination through general practitioner surgeries specialising in HIV. We also provide volunteer home carers for people with a dual diagnosis of HIV and a mental health condition.

In our experience people living with HIV/AIDS and a mental health diagnosis have on occasion received sub-optimal care due to limited capacity of mental health facilities to refer to AIDS services or for some AIDS services to appropriately identify and refer to mental health services. This is due in part to resource allocation and misinterpretation of definitions related to mental health and the roles and responsibilities of carers and their coordination.

This submission comments specifically in relation to the effects of legislation on people who have a dual diagnosis of HIV and a mental health condition.

SUMMARY OF COMMENTS

1. The Mental Health Act contains a limited number of provisions for disclosure to the "relatives of a person". The current provisions do not resolve the common issue for Gay, Lesbian, Bisexual and Transgender (GLBT) people where family/relatives may be an inappropriate option. The legislation needs definition to include same sex life partners and or friends/'chosen family' or 'significant other' (at the individual's discretion).
2. Amended legislation should allow sharing of information with carers in circumstances where such information is required for on-going care and treatment (at the individual's discretion).
3. The person to whom the information is related should consent to disclosure, in line with therapeutic intervention guidelines. Disclosure without consent should only occur where admission or discharge occurs under the involuntary detention provisions of the Mental Health Act. Specifically such disclosure should only occur where the individual is to go before a Magistrate thus enabling the primary carer to be present at the hearing.

¹ Organic conditions include AIDS dementia complex (ADC), or any other neurological conditions causing mental health disturbance ie brain tumour. Non-organic conditions ie psychosocial/psychological includes reactive depression, anxiety, bipolar, or mental health changes resulting from treatments/medications.

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4. We would support the amendment option outlined in section 3.5.1 of the discussion paper wherein information is reasonably required for ongoing care and an individual is unable to give consent.

GENERAL CONCERNS ABOUT THE LANGUAGE OF THE DISCUSSION PAPER

Current legislation does not adequately permit the disclosure of information to carers for specific issues related to clinical care or admissions nor more generally to information for ongoing treatment and care. Furthermore the language and definitions in the current legislation and the discussion paper do not take into account the unique circumstance of same sex partner or carer. Nor does it differentiate between partner, carer or 'family'. This lack of definition or acknowledgment of same partners or 'chosen family' has led to sub-optimal care and lack of communication between service providers and primary carers/partners. This frequently results in the wishes of biological family members subsuming the wishes of individuals' life partners or nominated carers. This occurs even in instances where there has been no recent contact between the individuals in question and members of the biological family.

This lack of definition can be more acutely felt in the exercise or lack thereof a partners decision on behalf of the patient when the same sex partner is not recognised by church based service providers. Which leads in turn to the wishes of 'family' being upheld when in fact there is an absence of ongoing relationship between family and patient. The language and definitions need to be spelt out clearly so to enable partner/carer to be quite clear about their rights especially during an often emotionally fraught time, and service providers to be aware of their responsibility to patients' partner/carer regardless of their institutions attitude toward GLBT people.

Recommendation: The definition in Section 38 (4) needs to be amended to recognise the role of same sex life partners and the role of 'chosen family'.²

ISSUES IN RELATION TO ATTENDANCE AT A MAGISTRATE'S INQUIRY AND RECOGNITION OF CARERS IN THE MENTAL HEALTH ACT

Section 43 (2) should clearly identify the role of same sex partner and or carer, thereby overcoming the current bias of magistrates toward the relatives of a person rather than those involved in ongoing care and support. People living with HIV/AIDS (PLWHA) and a mental health condition frequently rely upon volunteer home care services and in the absence of close friendship networks, 'volunteer buddies' assigned by NGO's. This is especially true for PLWHA who have had their friendship networks decimated by the HIV epidemic and are totally reliant on a volunteer carer or buddy for their support.

² Chosen family is the term used to refer to friends who have a close on-going relationship of care and concern for mutual wellbeing

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Recommendation: The role of volunteer carer and/or buddy should be recognised and defined as a specific and unique relationship separate to the recognition and role of paid care service provision.

INCLUSION OF CARERS IN DISCHARGE PLANNING

Hospital discharge frequently occurs without informing carers/partners or relatives. Even more frequently discharge occurs in the absence of appropriate discharge planning: where the primary carer has not been involved in discharge planning. Currently ACON's Community Support Network participates in discharge planning at one major Sydney hospital. However, most hospitals do not recognise the role of community volunteer care and support services, and therefore do not provide an opportunity to include them in discharge care and support planning. Similarly carer/same sex partner participation only occurs on an ad hoc basis at most hospitals. The role of carers/partners needs to be outlined clearly to inform both the carers/partners of their rights and hospitals in carers' role in relation to discharge planning.

Recommendation: Section 293 (1) of the Mental Health Act should articulate the role of carers and same sex partners in relation to discharge planning.

LEGISLATIVE OPTIONS IN SETTING THE BOUNDARIES

The language of this discussion paper mirrors that in various pieces of legislation wherein the terms 'carer', 'relative', 'close friend' and 'person responsible' are interchanged to define different relationships. The Guardianship Act 1987 provides a clear example of carer definition, which should be used to amend the Mental Health Act, similarly its definition of 'person responsible' and 'close friend'. None of the definitions used in the Acts contained in the appendix of this discussion paper provide a definition of partner for the purposes of a same sex relationship.

ACON believes that in order for a definition of carer to be meaningful it should be limited to those who provide care or have frequent personal contact and a personal interest in the other person's welfare (other than for remuneration). The definition should not be automatically conferred on the basis of biological relationship. Relatives who are not directly involved in care or who do not have frequent personal contact and a personal interest in the other person's welfare should only be considered as a carer in the absence of all other defined carer or partner relationships.

Similarly definition of same sex partner should be that of an individual, who has an ongoing relationship inextricably linked to the care and concern for the welfare of the other person. This definition should not be contingent on cohabitation.

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A person who is deemed to have capacity has an inalienable right to prevent access to information by family, partner, carer or friend.

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Recommendation: A person should have the right to prevent access to information by carers, partners, or 'person responsible' when that person has capacity.

IN CONCLUSION SUMMARY OF RECOMMENDATIONS

Recommendation: The definition in Section 38 (4) needs to be amended to recognise the role of same sex partners and the role of 'chosen family'.³

Recommendation: The role of volunteer carer and/or buddy (Sect: 38/4) should be recognised and defined as a specific and unique relationship separate to the recognition and role of paid care service provision.

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³ Chosen family is the term used to refer to friends who have a close on-going relationship of care and concern for mutual wellbeing