POLICY STATEMENT 8

CARER SUPPORT

Background

Lived Experience Australia believes that there is insufficient acknowledgment of and support for the indispensable role of carers in the provision of both private and public mental health services in Australia. In this context, **a primary carer** may be defined as a family member, partner, friend neighbour, or other person who regularly cares for a person with a mental illness.

The role of the carer in service delivery is often ignored, rejected or seriously undervalued. In some cases, this appears to be a response to the requirement that consumer privacy be protected. However, the carer's rights are not observed nearly so assiduously. This has particular significance when the consumers are young people who are still the financial and psychological responsibility of their parents.

Lived Experience Australia believes that in order to reduce tokenistic interaction between carers, consumers and health professionals, and give due recognition to the fundamental role of carers in service delivery, the following changes are required:

- The indispensable role of carers and their contribution to the wellbeing of consumers must be officially acknowledged.

- Carers, with the consent of the consumers they act for, should be consulted, engaged and have real input, wherever possible, in the formulation of consumer treatment plans, including admission, medication requirements, consumer progress and discharge.

- Carers require greater access to health professionals including doctors, psychologists and primary nurses, when the person they are caring for is hospitalised. Greater utilisation of their knowledge of consumers and their 'lived experiences' is also needed.

- Carers require information about a range of issues such as diagnosis, medications, side effects etc.

- There is a need for carers to be educated in their caring roles. Things such as what to do in a crisis etc.

- Carers need substantially more educational opportunities for gaining the information and skills necessary for self–care and utilising community resources, especially support groups and crisis services.

- There should be guaranteed funding of respite for carers, as well as for consumers.

- Legalistic information, such as privacy guidelines and requirements for becoming a full–time carer and/or power of attorney, should be made more readily available to carers.

- In the light of their diverse and demanding responsibilities, it is clear that *full–time* carers require a much higher level of remuneration than they currently receive.

- The needs of carers in remote areas require particular attention. There is a lack of support groups for carers in rural areas and it is imperative that there be financial support for geographically isolated carers in order to meet travel and accommodation costs when consumers are admitted to urban hospitals.

In addition, there are particular changes required in the private mental health system. The role, adequacy of information, education, and support for primary carers in private sector settings is not currently valued to the extent it should be. Whilst there is some controversy, almost all programs provided by private hospitals with psychiatric beds aimed at educating, informing and supporting carers, are not financially supported in their own right by private health insurance funds. Hospitals providing this type of program do so at their own expense.

Policy

1. With the consent of the consumer, implement a process of formal identification by the consumer of a nominated Carer including the extent to which information is to be shared, that is limited information to full information sharing.

2. If the consumer declines to nominate their carer in the first instance, then a process should be implemented to review this position on a regular basis.

3. Adequate information and education must be developed and provided to carers in a variety of mediums by providers and funders of the private mental health sector.

4. There should be early provision of information regarding available support.

5. That the *Carer Payment* be reviewed, as a matter of urgency, to enable those people caring for someone with a mental illness to be eligible for the Payment (currently, Carers are not eligible or find it extremely difficult to access because of the nature of the illness and current requirements for eligibility of the Carers Payment).

6. The amount paid under the *Carer Allowance* also needs to be reviewed, as the current amount is manifestly inadequate to sustain Carers in their full–time caring role.

7. The use of interpreters must be engaged when the carer is from a Non–English speaking background, or where disabilities preclude adequate information exchange.

8. Carers in remote areas should be advised of available telephone and internet support.

Policy approved: October, 2012