



DISCUSSION PAPER 1

MODELS FOR CONSUMER AND CARER PARTICIPATION WITHIN THE PRIVATE SECTOR

Background

In terms of consumer and carer participation, it has been determined that there are essentially four elements to this participation.

The first element refers to the rights of consumers to actively participate in decisions being made about themselves at the individual treatment or micro level and, with their permission, the carers right to also participate in those decisions, as much as possible.

The second element of participation refers to consumers and carers involved in local or service level. This relates to their roles as peer support workers and consumer and carer consultants. This work predominantly involves working at the service delivery level with consumers in acute inpatient settings. Their role should include membership of committees which plan, implement and evaluate various aspects of the services delivered by individual mental health settings.

The third element refers to participation at a State or Territory level which involves such things as membership of key committees/working groups, selection panels, liaison with other consumer or non government organisations.

Finally, the fourth element refers to participation of a lesser number of consumers and carers involved at the national level with such things as the determination of policy, governance, formal evaluation, innovation in delivery and forward thinking about the sector as a whole.

The current situation

Throughout the 1990s and since, Australian government policies require public mental health services to encourage the participation of consumers and carers in the development, implementation, delivery and evaluation of their services. There is an increasing demand by consumers and carers for greater participation at this level.

For the private sector, much consumer and carer involvement at the macro or service/systemic level within private hospitals remains difficult to establish and maintain. Private hospitals operate within a commercial environment with

Agreements negotiated confidentially with funders known as 'Hospital Purchaser Provider Agreements'. The licensing of Private hospitals also differs from that of public hospitals as does the insurable liabilities.

Many private hospital administrators are concerned about consumer and carer participation at the service delivery level because of confidentiality, commercial risks and possible litigation. This has seen a very slow uptake of roles for consumers and carers as consultants and, if at all, as peer support workers. The Network at the time of writing this Position Statement is unaware of ANY peer support workers within the private hospital setting.

What is genuine and effective participation?

For there to be genuine and effective systemic consumer and carer participation in the public and private mental health sectors, consumers and carers must have opportunities to participate at management levels.

How do we achieve this ideal?

The terms 'consultant' and 'advocate' are often used interchangeably, but the Network prefers the former. When we look to the experiences of the public sector, anecdotal evidence suggests that service providers frequently view 'advocates' in the same way that many employers regard trade union officials. The 'them-and-us' syndrome invariably gives rise to conflict and hostility, and is generally to the detriment of consumers and carers. We have seen in the public sector the accepted positions of peer support workers. This is interesting as many service providers find the term 'peer support workers' more acceptable than consumer 'consultants' believing the term consultant elevates the consumer worker to a higher level of recognition.

Tasmania and the ACT have released consumer and carer participation frameworks which recognise the vital role of consumer and carer consultants. Both consumer and, to a lesser extent, carer consultants are currently employed in the public sector throughout Australia. Victoria and New South Wales have one consumer consultant each in the private sector, but no State or Territory has carer consultants in the private sector.

Outline of four models

Consumer and Carer Consultants

The Network recognises that a number of private hospitals in Victoria employ Consumer Consultants and one hospital has employed a Carer Consultant. In New South Wales, the one Consumer Consultant is employed by two private hospitals.

Consumer and carer consultants work with consumers and carers generally and service providers in what aims to be a genuine partnership. They introduce consumer and carer perspectives and attitudes, increase the responsiveness of service providers to consumer and carer needs, and provide a voice for consumers and carers. Consumer and Carer Consultants

should be employed on the basis of their expertise gained through experience of the mental health system.

Consultants are employees of the services and are usually employed on a part-time basis. There is often the expectation that they will be involved in systemic reform through, for example, committee membership, selection panels, staff education and training, and feedback about services. We are not aware of any current State/Territory or Commonwealth guidelines for the employment, training, remuneration and support of consultants. This is compounded by the fact that in the private sector a consumer consultant may be employed by more than one hospital as is the case in NSW and Victoria. The lack of guidelines is unfortunate because it may reinforce the service provider perception that the consultant is merely an employee that may be expendable.

Ideally, consultants are employed on the same basis as other staff. They have access to the same resources as other staff, are invited to staff meetings, staff refer consumers and carers to them, they can make recommendations to improve service delivery, or introduce new services and are involved in both strategic and operational planning. They interact with consumers or carers within the hospital setting, offering factual information only, and do not provide clinical advice to consumers or carers.

Consumer and Carer Advisory Committees

In the private mental health sector systemic consumer and carer participation usually translates into a few representatives being members of the private hospitals' Consumer and Carer Advisory Committees. Whilst this can be innovative and may give some representatives an input into service delivery, it can be restrictive in practice since it may prevent their involvement in 'big-picture' reform.

Many private hospitals report that it is very difficult to attract suitable consumers and carers into the positions on their Consumer and Carer Advisory Committees for a number of reasons. They further report that those representatives are very hard to retain.

Many consumer and carer representatives are unpaid, whilst a few receive payment via sitting fees of around \$50 per hour for the two or so hours they are involved. They are not employees of the private hospital.

Their role does not generally involve direct consumer or carer contact and where this occurs, is restricted to running focus groups around particular issues such as catering, satisfaction with aspects of the hospital, etc.

Innovative Model

We propose that an innovative approach, where private hospitals are struggling to sustain consumer and carer participation, could be the employment of one consumer and one carer consultant who may be retained by more than one facility. This might be advantageous for the smaller facilities

within a particular state. This is currently the situation in NSW where one consumer consultant is engaged by two private hospitals and employed on a part time basis by both facilities.

It might also be advantageous for the larger organisations of the same provider ie Ramsay Health Care, Healthscope, ehealthcare and others, where there are multiple facilities located within a particular state, that the one consumer and the one carer consultant could be employed within two or more of those private hospitals.

Expanded model

Should the above model be seen by private hospitals to be feasible, the consumer and carer consultant's role could be further supported by the establishment of a small core group of consumers and carers within each of the particular private hospitals.

Conclusion

The Network has set out herewith four possible models of consumer and carer participation within the private sector. The Network has provided these alternate models in recognition of the range of circumstances experienced by different private sector providers. Each of these models has different applicability.. and the Network does not strongly advocate for any one model.

However, the Network believes that consistency and sustainability in consumer and carer representation is vital. Based on the experiences of some consumer consultants and the consumer carer consultant currently employed in NSW and Victoria the Network believes that this is most likely obtained by way of the paid employment of consumer and carer consultants.

Accordingly, while the Network endorses all of four models presented, the Network favours the fourth or *expanded model* ,a combination of both the consultant model supported by a small consumer and carer advisory committee, where it is viable.