The importance of the consumer voice

Presentation to Life Without Barriers Breakfast
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Introduction

Outline

- Evidence based advocacy
- Consumer participation and the prevention of avoidable harm caused by services
- Consumer priorities and scientific evidence
- Recovery and human rights
- The need for peak consumer participation

Good Morning.

Thankyou for the opportunity to talk on the topic of consumer voice, and describe how I envisage the advocacy role of the Office of the Public Advocate.

I to wish to acknowledge the Kaurna people, the traditional owners of the land on which we meet, and the importance of the link to this land for the Kaurna people of today.

Today I will discuss how consumers lived experience, can inform evidence based advocacy and why consumers speaking up is a key strategy for making health services safe. I will then give examples where consumers have picked critical issues early, and by listening to what consumers want, our systems

can get things right sooner. To conclude I will note the link between recovery, consumer involvement, human rights, and the need for effective peak consumer participation.

Public Advocate

(a)to keep under review, within both the public and the private sector, all programmes designed to meet the needs of mentally incapacitated persons;

(b)to identify any areas of unmet needs, or inappropriately met needs, of mentally incapacitated persons and to recommend to the Minister the development of programmes for meeting those needs or the improvement of existing programmes;

(c)to speak for and promote the rights and interests of any class of mentally incapacitated persons or of mentally incapacitated persons generally;

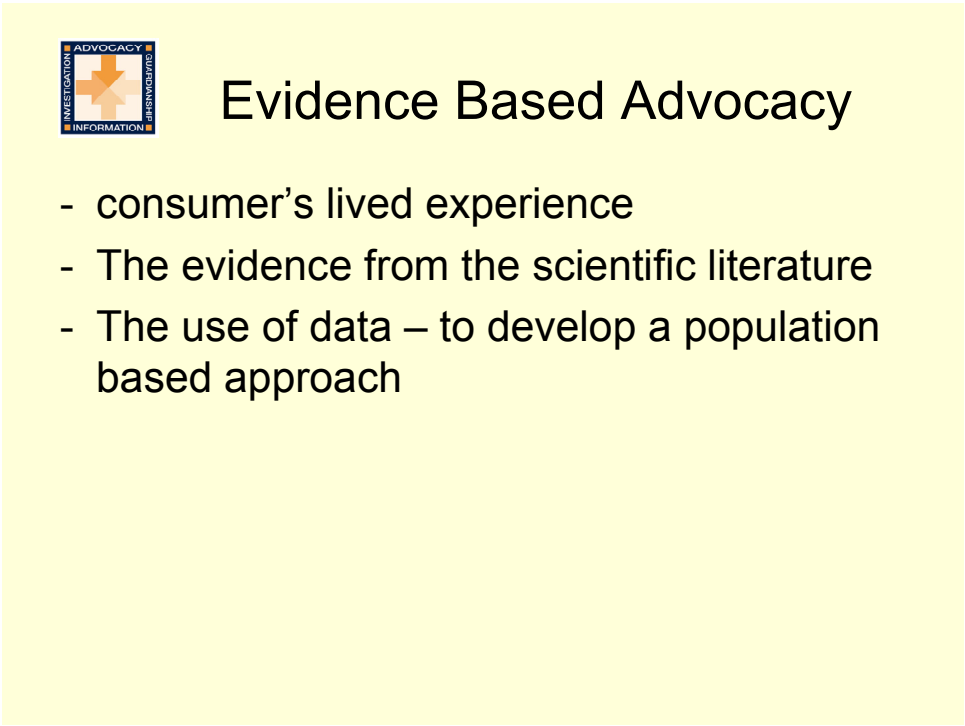
(e)to give support to and promote the interests of carers of mentally incapacitated persons;

This slide describes systems advocacy of the Public Advocate listed in the Guardianship & Administration Act 1993. The key elements include reviewing programs both public and private, identifying unmet needs, recommending to the minister new programs, or improvements to existing programs, speaking for and promoting the rights and interests of persons, and their carers. It is an independent statutory role accountable to parliament.

The Public Advocate works across the sectors of mental health, disability, and aged care. Principles are similar. For example mental health recovery approaches, have been informed by concepts of citizenship developed in the disability sector.

The legislation refers to mentally incapacitated persons. In the mental health setting this is people who are detained, could be detained, have been

detained or have an involuntary community treatment order, or guardianship order in place.



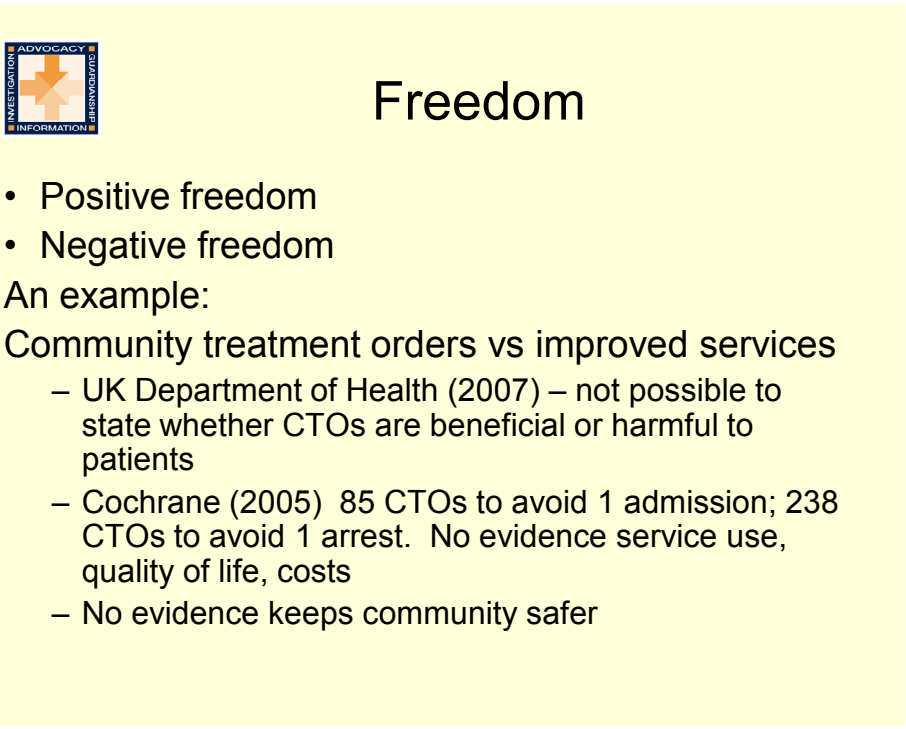
I will use an evidence based advocacy approach.

I have listed three sources of evidence: consumers lived experience, evidence from the literature about what works and what doesn't and data, so that we can use numbers to effectively advocate for groups as well as individuals.

Any argument should stand on the evidence of that argument not on who is saying it. I believe that lived experience, literature evidence, and data about populations provide an effective evidence base.

For further context I should let you know that the office is appointed as guardian of last resort for about 440 people. We also conduct investigations, provide education and operate an enquiry service. Our staff are very busy with guardian work and this limits time spent on systems advocacy. But we

can still be effective in our role if we collaborate well with consumers and the sector in general.



Underpinning this work is the core issue of freedom. Negative freedom is the freedom from restraint. In mental health this would be the freedom from unnecessary detention, or unnecessary community treatment orders.

Positive freedom is the opportunity and freedom to fulfil ones potential, in the same way that any citizen can pursue their goals. To have a life worth living. Positive freedom can be limited by a lack of services - if you need rehabilitation and good clinical care to do what you want to do with your life, and you can't get that, your life will be limited. Positive freedom is the essence of recovery.

Community Treatment Orders illustrate the balance between negative and positive freedoms, and the need to consider evidence.

A community treatment order allows a person to be administered treatment against their will. They have been in common use in mental health in this country for many years. They have been recently introduced to the United Kingdom after much debate.

The evidence of their effectiveness is very limited. More research is needed. I have cited a paper published last year by academics for the UK Dept of Health (Churchill et al 2007). The reviewers concluded that is not possible to state whether CTOs are beneficial or harmful to patients. This outcome followed a Cochrane review two years beforehand.

The Cochrane collaboration is highly regarded for undertaking evidence based reviews. This review (Kisely et al, 2005) found no evidence that CTO's effect service use, quality of life or costs. Within the limited evidence were results that can be used to question the assumption that a CTO is a less restrictive option. A CTO is argued to be less restrictive because it avoids hospitalisation. The review used an analysis to conclude that it is necessary to issue 85 CTO's to avoid one admission, 238 CTO's to avoid one arrest. Studies have not provided evidence that CTOs keep the community safe.

We have CTO's. The recent legislation review in this state will extend their use and this has been broadly supported. The lack of evidence does not necessarily mean that CTOs should be abandoned. Rather they need to be used with much consideration, and the use of CTO's needs to be monitored.

Review of act

(f)to give advice on the powers that may be exercised under this Act in relation to mentally incapacitated persons, on the operation of this Act generally and on appropriate alternatives to taking action under this Act;

This is another function of the Public Advocate. Advising on powers, and importantly appropriate alternatives to using those powers.

To do this we will be soon auditing a sample of detentions and in the future reviewing Community Treatment Orders and how they are used. This information will inform the training required for people who initiate detention or commence community treatment orders in the future.

The point of the CTO example is that while there is very limited evidence of the effectiveness of CTO's (if any), but in contrast there is very strong evidence about the effectiveness of assertive community treatment (for example Marshall and Lockwood, 1998). Assertive community treatment is the combined work of psychosocial rehabilitation and clinical services.

On one hand there is a positive freedom - assertive rehabilitation, early intervention and holistic services that people may want and many might voluntarily choose to go to. These are proven. In contrast the evidence to support the imposition of compulsory treatment - the justification of negative freedom is poor. There is a risk that if there are insufficient effective services,

this might increase the use of compulsory community treatment. The positive freedoms and the access to rehabilitation to create opportunity, is balanced against the negative freedom of restriction and compulsion.

Consumer participation and safety

- Prevention of avoidable errors in healthcare
- Recovery principles provide for safe health care

Consumer participation is a recognised strategy to make health services safe (for example Scott et al, 2008). Consumers see all of the system during their journey. Staff are generally familiar with their own bit. Staff of any discipline may take great pride in doing their job well and diligently, but the benefit for a consumer is lost if all the bits do no fit together. In general health, mental health, and disability systems consumers, need to be a central participant in redesign for this reason.

Patient safety reviews make it clear that organisations must make consumers feel safe to speak up and to challenge providers when they believe something is going wrong. In general health this questioning without retribution may help prevent a medication error if a person is about to be given the wrong drug, or even worse if a consumer is about to be given the wrong investigation or wrong procedure meant for someone else.

Assertive consumers are more likely to ask for the right care, and intervene when something is about to go wrong.

Similar principles apply in mental health, as services tackle key safety objectives - the prevention of suicide, the minimisation of seclusion and restraint, reducing medication errors, and safe transport (National Mental Health Working Group, 2005).

At times when a person may be too unwell to challenge or ask the question others need to do this. Providers regularly take on this advocacy role within their organisation and across organisations.

Incidental to this I would also note that in our office as guardians of last resort, we have to take the stance of assertive health consumers when we are asked to agree to a proposed treatment on behalf of a person under guardianship.

Consumer priorities

- The report revealed that “a fundamental difference in perspective was evident between those who used services at a local or district level and those who administered services.”
- Within the report noted that consumers and their family and carers surveyed prioritised a number of fundamental aspects of health care and related services, which included
  - A greater emphasis on holistic care and response to individual needs,
  - Treatment with dignity and concern for the individual,
  - Respect for the legitimate interests of family and carers, and
  - Ability to meet social, emotional, mental and physical health needs.

This comes from the Not for Service report (Mental Health Council of Australia, 2005). Their can be significant differences between consumer priorities and organisational priorities. This is a subject in itself.

What was noted in the report was that consumers and carers wanted (amongst other requests) a greater emphasis on holistic care, treatment with dignity and concern for the individual, respect for the interest of families and carers, and the ability to meet social and emotional, as well as physical and mental health needs.

The solution to this is consumer representation as systems are redesigned across sectors. Consumers need to be given problems early to consider. If they are involved late and asked to comment on completed solutions, the full value of consumer input will be lost because consumers will be constrained in their response by the format and structure to a solution that is already offered which will be an organisational based format. This is particularly relevant now because at a state level there has been uncertainty about how peak consumer input will be developed, and how representatives from city and country can meet together to consider proposals. Administrators meet together to develop plans, consumers should do so as well.

Experienced consumer representatives are also expert at speaking to other consumers, eliciting views that staff may not elicit (Archer, 2002), and then bringing this to the table.

Lived experience and evidence

- Two examples (out of many)
  - Post discharge follow-up with involvement of families
  - The holistic approach to mental health care

Consumers recognise big issues first, often well before it is on the policy or academic agenda.

I give some examples that I am familiar with in the last 10 years.

10 years ago consumers were very concerned about post discharge care. They believed after periods in hospital consumers have difficulty with day to day tasks, need earlier clinical review, as well as support services. These needs were not usually prioritised by administrators.

Subsequently the post discharge period has been recognised in safety reports such as NSW Tracking Tragedy as a high risk period (NSW Mental Health Sentinel Events Committee, 2005) often characterised by poor communication and poor co-ordination of care. In particular for the high risk first 7 days after leaving hospital. Now effective and predictable post discharge care is part of the National Safety Plan for mental health (National Mental Health Working Group, 2005).

The next example is the holistic approach. Consumer representatives have known for a long time that they and fellow consumers do not divide their problems according to the specialist structure of health services. Physical and mental health are related, and attending to broad health needs is a way mental health services can reach out to consumers who otherwise may not accept pure mental health care (for example Chronic Condition Self Management programs).

In recent years surveys, in Australia and overseas have described the poor physical health of mental health consumers, and action is starting to be taken. The WA physical health and mental health survey (Coghlan et al, 2001) showed that MH consumers have 2.5 times the mortality of the rest of the population, 16% of excess deaths are due to heart disease. Consumers want holistic care and they need it. Physical health check ups, assistance with good diets on a budget, exercise and physical activity can be part of a psychosocial holistic rehabilitation program.

Recovery and human rights

- Recovery vs restriction
- Recovery as a safe model of care

I have already mentioned recovery and positive freedoms. Consumers have been the standard bearer for the recovery approach in many parts of Australia

including South Australia, and recovery based programs deliver positive outcomes for their consumers. Yet it is still being debated with in our care system. Critics, who may have seen their clients failed by mental health services, tell the media and government that recovery is flawed.

Just because recovery has been accepted as a national policy in this country and in other countries, does not mean that the struggle is over.

An example of the success of recovery is the reduction of seclusion and restraint achieved through the application of recovery principles (for example Currie, 2005 describing the American program). This is another example of the balance between positive and negative freedoms. It is possible to dramatically reduce seclusion and restraint without putting staff at risk. It requires this respect for the individual, and involving them in plans for their care, if they become unwell or a person is unsettled or agitated, the response is personalised and works for that individual.

So, recovery rather than being something vague and aspirational, has a very hard edge. It makes a difference to peoples outcomes, and it can prevent restraint and unnecessary trauma.

Recovery is about positive freedom facilitated by effective psychosocial rehabilitation. It is not about putting other people at risk. The opposite of recovery is restriction. With restriction is lost opportunity, and if you take the case of avoidable seclusion and restraint it is also trauma and suffering.

Conclusion

- Evidence based advocacy
- Consumer participation and the prevention of avoidable harm caused by services
- Consumer priorities and evidence
- Recovery and human rights
- The need for peak consumer participation

As I work in this new position I want to hear from you about the issues. If you disagree with what I put forward, please do not hesitate to call, email with your views. I will do my best to apply an evidence based approach so that the potential of this independent statutory office can be fully used for the good purposes it was created for.

So in summary I trust I have made a case for evidence based advocacy while linking consumer participation to recovery, and a recovery approach to fundamental rights. This can be supported by robust and peak consumer representation in this state.

As Public Advocate I look forward to working with you all in the years to come.

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