ADVOACY – more questions than answers.

For the purpose of exploring some of the emerging issues surrounding the role of 'consumer advocacy, three people with backgrounds in this field were asked to respond to the following questions.

Sandy Watson

1. The national standards for mental health services promote consumer participation, and as a consequence, many services have developed a consumer advocacy program. Do you think this has resulted in any confusion with consumer advocacy?

No-one can answer this question fully as there is no comprehensive research about consumer advocacy in NSW, as it is currently being practised, but the answer is an emphatic YES!

a) 'Consumer advocacy' as a practice, is poorly defined. It is a distinct type of advocacy, but few people have thought this through, or understood its ethical and practical dimensions.
b) Most consumer advocates think that their practice is adequately covered by a form of advocacy known as 'Individual' advocacy. This is seriously problematic because it is the exact opposite type of advocacy to that which ought to be practised.
c) There is no skills-based training for consumer advocates.
d) Consumers have no credible industrial award, most are employed as Health Education Officers. This leads to confusion because some consumers think of themselves as 'health workers'. They are **not** providing any **health services**.
e) Many consumers blur the boundary between advocacy practice, and other practices such as counselling, mediation, alternative healing (often with the imprimatur of the service…)
f) Many consumer advocates breach the rights of the consumers who they are there to protect.
g) Some consumer advocates are restricted to being able to undertake 'Systems' advocacy only. This is seriously flawed.
h) Many advocates have advocacy tagged onto other roles, such as provision of social support etc. Consumer advocacy should never be confused with other consumer roles.
i) People mistakenly believe that consumers can't provide advocacy in the same service that employs them. This is nonsense. However, advocacy must be designed to be independent and autonomous from service delivery.
j) The quality of consumer advocacy varies so widely that it is a cause of great concern.

2. **Is it useful to use the term Consumer Consultant for consumer employees of a health service?**

No! Unfortunately this term was used in the first project in Australia (Rozelle) to employ consumers to provide services within the hospital. A Consumer Consultant should be considered to be an external person, brought in to consult, or provide a specific service on the basis that they are external.

3. **What do you think should be the role of a successful consumer advocate and is this the same role as a Consumer Consultant?**

A consumer advocate should be called such, and employed, in a specific advocacy role, with a job description that fits consumer advocacy, and not a whole lot of other irrelevant stuff. In the simplest of terms, a consumer advocate's role is:

a) train, support, educate and/or resource consumers to speak up on their own behalf (Self Advocacy)
b) raise and act upon systemic issues of concern, that have or may have an unwanted impact on consumers receiving or trying to receive a service (Systemic Advocacy)
c) provide an Individual advocacy service to a consumer if and when they are unable to advocate on their own behalf, for whatever reason, and they give consent for you to do so (Individual Advocacy – speak on anothers' behalf)
d) promote and protect all of the rights of all consumers in the service, without fear or favour
e) refer consumers to more appropriate advocacy if the circumstance requires a different form of advocacy or an advocate with more resources/power to act
f) write timely reports, (unidentified) in relation to the issues that arise, and furnish them to the appropriate person or committee within the service for feedback or review

4. **What consumer advocacy model would you propose?**

A model is a theoretical scheme. In theory, consumer advocacy should:

a) operate within every mental health service
b) always operate on the basis that three types of advocacy are employed in consumer advocacy, in the order that they are practised in true 'consumer advocacy', which is a distinct form of advocacy : 1. Self, 2. Systems, & 3. Individual (in limited circumstances)
c) have a clear ethical foundation (ethics of consumer advocacy)
d) have clear performance standards in conjunction with a set of practice guidelines for consumer advocacy
e) all advocates complete the same skills based training – TAFE accredited. No consumer advocate should work without completion of such training, and consumers should not receive certification if they can't satisfy training requirements. Training should be ongoing and mandatory.
f) the advocacy role should not be confused with other consumer roles, they need to be kept separate

g) a competent, independent organisation (funded by Health) should have carriage of developing, managing, training, supervising and overseeing a consumer advocacy program for all services. This way consumers could get experience working in different services and environments, they would be independent, and the quality of the work could have more of a guarantee than it does now. Reporting could have more of a function than it does now, in flagging and alerting services to problems in the way they are functioning, not only within, but comparatively, in relation to other services.

h) An adequate number of hours should be made available for consumer advocates. It is tokenistic to provide for one or two hours of advocacy a week.

5. Are there any other questions that need to be asked?

a) Why is there little or no research being conducted on the consumer workforce?

b) Why is there no skills-based, accredited training being offered to consumer advocates who provide advocacy in the field of mental health?

c) How many consumer workers have completed a suicide whilst they were employed in consumer positions, and were these suicides related to the pressure of the work they were doing?

d) Why isn't there more funding to address these and other problems faced by consumers in the consumer workforce?

e) Why isn't there an appropriate award or industrial agreement for these workers?

f) What is the turnover rate for consumer workers? Why do they leave their jobs? What are the issues from their perspective?

g) Why are services allowed to employ consumers as advocates (often in psychiatric units) without providing them with any training whatsoever?

Phil Escott

With a range of descriptions of our job it is very easy to be confused. We call ourselves consumer advocates, consumer consultants, peer support workers, consumer representatives or consumer workers and there is great variation in job descriptions and consumers' assessment of their role.

When the first service in Australia was set up at Rozelle Hospital in 1993 the word 'consultant' was supported by some to give a positive spin to the job. It was really a play on words referring to the use of phrases such as consultant psychiatrist and also an attempt to point out the importance of the role. Now it is used to convey the variety and extent of the role, beyond just advocacy.

As the Rozelle group developed it was very much an inpatient service so it was natural that rights issues and on-the-ground advocacy would be central. However, as the National Mental Health Standards stated consumers had a right to be involved in the planning, delivery and evaluation of services at all levels. This implied educational work, representation on committees and having a greater say about the planning of services. It also mandated systems advocacy where big picture issues such as funding levels, staffing and mental health promotion were important part of the role as well.

Add to this the development of a consumer movement with its own perspective and political objectives and differences and we have the beginnings of a set of problems:

1. Can we refer to ourselves as advocates when our roles are much broader? There is no consensus that advocacy is even central to the job.
2. Are we taking on too much and forgetting our core business, which to me centres on the promotion of consumer rights and their empowerment.
3. Is the consumer consultant role becoming too big and are we forgetting our limitations – the things we can do and realistically the things we can't do?
4. What should we call ourselves – consumer advocates, consumer consultants or consumer workers? Or even as some imply, mental health staff?
5. Do all of us have a good grasp of the underpinnings of a recovery focus, which to me is central to our work?
6. Do we all have the basic standard training to work in inpatient and community settings?
7. Can we call ourselves independent advocates when we are also employees of Area Mental Health services? I think Official Visitors have more independence.

Frankly, the number of consumer workers across the State is a little disappointing considering the amount of positive assessment in the literature – no more than 150 workers, most with minimal hours and some services have let go of all their advocates. What we call ourselves does vary and the rhetoric of participation does not match the reality as we struggle with sluggish bureaucracies and an ongoing battle to prove our worth. Perhaps, as a start, we need a national conference to sort out these issues.

Janet Meagher

After thirteen years of paid consumer advocacy in Australia, there are some real issues emerging. Some of these issues are occurring at a local level, some are spontaneously appearing at multiple places in a local area and some are becoming apparent at a broader level, regionally, across a state and nationally.

As to the reason why they are occurring at all, or who, or what, is behind these occurrences is a complex and debatable topic. In this short piece I shall only point to some of the obvious factors and trust that in due course appropriate attention is paid to a more erudite and in-depth investigation into these matters that will point to some ways forward perhaps through comprehensive reform of advocacy programs.

In Phil's contribution there are issues discussed around the following:

- Role confusion and role expansion
- "Core business" of advocacy
- Need for training
- Confusion in terminology
- Conflict with advocacy & Health Service employee roles
- Minimal hours allocated to these roles with many expectations creating a disproportion between rhetoric of participation and actual pressure to get the job done
- Conference to resolve these matters required.

In Sandy's discussion there are some pressing matters raised which can perhaps be summarized as:

- There is a great deal of confusion around the words, practice, quality, ethics and experience of consumer advocacy
- Need for training: skills based, quality focused and formally accredited
- Role needs to be quite specific & separate from other roles or services
- Industrial Award situation requires clarification
- Independent organization to manage advocacy matters, incl training & reporting
- Hours allocated to advocacy , usually inadequate
- Research on consumer workers, their pressures , health, support, turnover rate, issues

Each contributor has given us the substance of a debate that needs to happen, that MUST happen in a sequence that allows all issues to be placed on the table for analysis and discussion, eventually culminating in resolutions and enhanced understanding of advocacy in all its forms in the Mental Health Services and Non Government Sector.
My suggested sequence for the debate on consumer advocacy would be as follows:-

1. Consumers critique, discuss and analyse the present situation and circumstances of advocacy as outlined by Sandy and Phil.
2. Consumers involve consumer experts and leaders to inform their discussions, draw up definitions, propose advocacy criteria and agree on role descriptions.
3. Consumers refine ideas, draw up model processes, incorporate definitions into the roles and integrate advocacy criteria and protocols into proposals.
4. Consumers and lead agencies/departments discuss outcomes of steps 1-3 and draw up action plans and proposals.
5. Relevant agencies/departments and stakeholders work on fulfilling action plans, securing any necessary agreements, allocating and drawing up protocols and contracts.
6. Outcomes of the debate would possibly include a scenario something like this:-

    - **Advocacy training** available to consumers in every state and territory. Such training would be
        - Based on a consumer designed curriculum and syllabus incorporating rights, ethics, empowerment, and other core issues.
        - Presented by experienced qualified consumer tutor/s
        - Accredited, and participants assessed under competency criteria
        - Nationally recognized qualification
        - Paid for by employer [if attending to qualify for existing paid consumer advocacy /consultancy position].
        - Future advocate/consumer consultant positions to require this qualification as an essential criteria for job applicants.

    - Consumer Advocates/consumer consultants to be **employed independently** of a Health Service or Non Government Organization and contracted to the Service (or NGO) for their services.
      This would ensure a lessening of the pressures regarding frequent conflicts of interest, compromised values or consumer ethics. Perhaps an agency could be set up in States/Territories to provide such services.

- Consistent and agreed **National Standards of Consumer Advocacy** be established to inform all advocates and stakeholders.
- Consistent and agreed **employment contracts, codes of ethics/ conduct and salary scales** being implemented.
- Advocacy and consumer consultancy be overseen by a **national consumer advocacy steering committee**. Perhaps this could be an off-shoot of the Australian Mental Health Consumer Network. This body could oversee disciplinary and grievance mechanisms and oversee accreditation of these consumer roles.

In summary, I'd like to see consumer advocacy move beyond the currently accepted standard to the next level. A level of greater independence that is counterbalanced by a more informed and accredited consumer worker. This worker will have real opportunities to move through a career structure based on agreed standards of performance and will report in a consumer friendly framework which will lessen the potential to cause conflict or compromises within the role. This will enhance relationships with the contracted service or organization and enable the consumer worker to more readily comply with the consumer's agreed Codes of Ethics. Let the debate commence!

N.B. These comments are made by the respondents as independent people, and are not made on behalf of any organisation or group.

If you would like to continue this debate please write with your comments to the Editor at Stephanie@mhcc.org.au

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View from the Peak