

**Presentation 25 March 2004  
NGO Conference Novotel  
on behalf of NSW Institute of Psychiatry.**

**Introduction**

- NSW Institute of Psychiatry Consumer Course
- I am co-ordinator of the Consumer Advocacy Course
- Ran 6 last year – 4 on campus in Parramatta, 2 off campus courses.
- Attendance from a range of consumers, mostly from within the public mental health sector –(employees, representatives), consumers from NGOs, consumers on their own behalf, consumers from private mental health services – have a mix of levels, ranging from consumers who just heard about the consumer movement yesterday, to consumers with post grad degrees in psychology, social work or law.

**Terminology** – my usage of the term **consumer** is to describe Consumer Advocacy Course participants, all of whom have to have, or have had a mental illness, in order to be eligible to do the course. I use the term ‘**consumer workforce**’ to describe consumers who are employed full or part time, or paid as casual employees to carry out consumer designated roles such as Consumer Co-ordination, Consumer Support Work and Consumer Advocacy.

**Scope**

- From my perspective as a trainer for the NSW Institute of Psychiatry, I want to highlight problems apparent amongst advocates who attend the Consumer Advocacy Course, problems that raise important questions about the quality and credibility of mental health consumer advocacy in NSW, whether in public, private or NGO services. I limit my presentation to 8 themes:
  1. Confusion over job titles for the consumer workforce and some of the problems this creates
  2. The lack of any relevant award for the consumer workforce and the dangers implicit in this issue
  3. The absence of skills based training and the failure of many services to provide any training for their consumer workforce and consumer representatives.
  4. The lack of any agreed upon ethics and principles for consumer advocacy, following from which there is a failure to define

consumer advocacy practice as distinct from other advocacy practice. There are many advocates working in the dark, often acting unethically without knowing it.

5. Line managers within services usually have had no training about consumer participation or advocacy. There is very little by way of staff training about consumer perspectives and participation, let alone about understanding the needs of a consumer workforce.
6. Some consumer workers are operating in complete isolation.
7. Some consumer workers are the new 'back-fill', fulfilling tasks that were, or are the work of other staff in the service.
8. Many consumer advocate positions lack the necessary independence to fulfil the most basic principle of advocacy, ie, that it is autonomous and independent from service delivery.

### Summary of issues

#### **1. Confusion over job titles for the consumer workforce and some of the problems this creates**

- There are far too many job titles for consumer workers in NSW. Consumers can variously be called Consumer Support Workers, Consumer Advocates, Consumer Consultants, Consumer Co-ordinators, Consumer Team Leaders etc. There are many others.
- Job descriptions are sometimes vague, or over-expansive. There are even job descriptions that bear no relationship to the job title. A consumer employee whose sole job it is to organize a cooking class and a bus trip, is called a 'Consumer Consultant'. This person does no consulting or advocacy, in fact had never heard of the word advocacy prior to doing the course. There is a lack of definition across the state of the core competencies that accompany various job titles. People working as **Consumer Support Workers** in NSW often work in ways that contradict one another across services: some develop volunteer programs, others oppose this. Many **Consumer Advocates** are operating with little rights knowledge, and don't meet basic competency standards for an advocate. **Consumer Co-ordinators** often work without any management training, sometimes over a period of years - despite the fact they directly manage consumer employees and/or representatives.
- Boundary blurring is common in NSW. **Consumer Advocates** in some services are doing all manner of inappropriate 'pseudo-clinical' tasks such as provision of alternative healing, provision of medication information, sitting on clinical teams, counseling, most disturbing of all advocates in one service routinely passing on information about the mental health of clients at a drop in centre to their case managers without the client's knowledge or consent. These tasks are not the domain of advocates, and clinical liaison dimension to advocacy needs to stop. If consumers want to be clinicians they should undertake the training, qualify and seek relevant clinical positions.

## **2 The lack of any relevant award for the consumer workforce and the dangers implicit in this issue**

- There is no relevant award for the consumer workforce. Consumer workers are usually employed under one of two awards – usually but not always as ‘Health Education Officers’, and less often as ‘Welfare Workers’. Neither award remotely relates to the work that consumer workers ought to do. Consequently, some consumer workers see themselves as ‘Welfare workers’ or ‘Health workers’ and act accordingly. They are neither. A further complication is that a significant proportion of the consumer workforce who have attended the Consumer Advocacy Course are fully qualified in various health or allied health fields such as psychology, social work, welfare work, psychiatric or general nursing. The point perhaps needs to be made that consumers who are trained in health or allied health professions ought to obtain employment in those professions if they want to do the work of counseling or the provision of therapy or rehabilitation, and ought therefore be accountable to their respective professional bodies for what they do in a workplace. Some systemic problems could be eliminated with the advent of a specific Consumer Workers Award:- conditions developed that protect consumers from exploitation, such as being pressured to do tasks that are the domain of other staff. I note that some consumer workers are deeply concerned about the lack of relevance surrounding their award.

## **3 The absence of skills based training and the failure of many services to provide any training for their consumer workforce and/or consumer representatives.**

- I am shocked at the fact that many consumers who come to the Consumer Advocacy Course are already operating as advocates in mental health services without any training whatsoever. It is not uncommon to encounter people who work in ward situations as advocates, who only receive a half-day orientation on the job prior to commencement, and simply don’t have the knowledge or the skills to work in such a complex environment and role. One consumer advocate had been working for seven years in the role without having received any advocacy training, demonstrating a bit of rights knowledge about the mental health act and the National Standards for Mental Health Services, and not much more. Many other advocates receive patchy training. In the absence of competency-based training, consumer advocacy standards are inconsistent. Disturbingly, some course participants have resistant attitudes towards core advocacy learning such as mental health policy, policies that often encompass consumer rights – going so far as to request that policy material be removed from the course. The fact that seemingly experienced advocates demonstrate such a poor grasp of the fundamental connections between rights, policy, and advocacy is worrying. Skills based accredited training must be introduced in NSW to raise the standard of the consumer workforce by training for specific roles, addressing theory, ethics and practice issues. Such training ought to be mandatory, carefully planned and supported by a range of agencies. In the absence of competency based training, many consumer workers are being set up to fail, and are experiencing significant and preventable workplace distress.

- 4. The lack of any agreed upon ethics and principles for consumer advocacy, following from which there is a failure to define ‘consumer advocacy practice’ as distinct from other advocacy practice. There are many advocates working in the dark, often acting unethically without knowing it.**

It amazes me that so little work has been done to define the practice of consumer advocacy: its ethics, principles and defining features. There are few materials available for consumer workers to draw down from for use as instruction. Much needs to be done to rectify this problem. Consumer advocacy is different from most other forms of advocacy, however many advocates are practising forms of advocacy that are inconsistent with the essential ethic of ‘self advocacy’ the tradition in which consumer advocacy truly resides. It is critical that work is done to clarify these matters, so that there is more transparency about the role of consumer advocate so as to reduce inappropriate advocacy practices. Not only would advocates benefit from the development of a substantive consumer worker manual covering theory, ethics, principles and practice issues pertaining to consumer advocacy: staff and line managers have considerable training needs that also need to be addressed, which brings me to my next theme.

- 5 Line managers and staff within services, usually are not exposed to any training about consumer participation, representation or advocacy. There is little by way of staff training about consumer perspectives and participation, let alone understanding the complex needs of a consumer workforce.**

- There is little or no training for staff, or for line managers in services employing or recruiting consumers into consumer specific roles. Staff are frequently poorly equipped to manage a consumer workforce, or to understand the role strain issues for consumer workers. Some line managers and staff present significant barriers to effective consumer advocacy and representation, whilst others work hard and sometimes make themselves vulnerable along the way, to enable consumer initiatives to succeed. It is simply unacceptable to place staff in positions where they line manage consumer workers, whilst having no current or even out of date awareness about the consumer activism, consumer literature and resources, critique, organizations and achievements.
- Training might alleviate some of the reported problems course participants are raising: being silenced, being made to do all representation within the service, not being allowed to consult with consumers, being asked to do things that are inappropriate, being intimidated for doing the very advocacy they are employed to undertake, being funded for few hours so as to keep advocacy projects at the level of tokenism. In my own experience training staff I encountered several senior staff who could readily see the need for their staff to undergo consumer participation training, but couldn’t see that they needed it to. Staff deserve access to training, so they can build up their confidence in a field that most of them received no training in whilst they were graduating.

## **6 Some consumer workers are operating in complete isolation.**

Many regional consumer advocacy projects have collapsed over the last decade. Some consumers work in such isolated conditions with little contact or networking support outside of their region. Whilst the Consumer Worker Forum meets annually to bring people together for a day, far more needs to occur to bring consumer workers together, offer them more substantive training, and opportunities to visit different consumer projects. Many participants in the course have no networking component to their practice, and know very little about other networks or consumer advocates who they could contact to follow up and obtain some casual mentoring, and I reiterate an earlier point that they often don't really know what advocacy is. Their attendance at the course is often their first real contact with their peers, they usually collect one another's details, but are often not resourced to make contact due to costs of telephone calls etc. Peer contact is a must, and it isn't happening to the degree it needs to.

## **7 Some consumer workers are the new 'back-fill', fulfilling tasks that were, or are the work of other staff in the service.**

- Throughout the consumer advocacy courses I have become aware that some consumer workers are the new 'back-fill'. By 'back-fill' I mean they fulfil tasks formerly taken by health or allied health staff some of whom are long gone, even when this falls outside of their job description: it isn't above some services to use consumer workers to do what I term 'pseudo rehabilitation' type work. When a creative arts position became vacant after a staff member left a public mental health service, the consumer co-ordinator took up the tasks of that staff member, even though the co-ordinator is the only consumer worker for a very large area, it simply wasn't their job but they took over the position and incorporated it into their own. Another consumer advocate saw nothing wrong with conducting alternative healing, a practice in completely contrary to advocacy practice. The lack of distinction pertaining to the role of advocacy is evidenced in many services, leading to inappropriate conduct and activity, which needs to be resolved. Others access medical records of patients, a practice that is again contrary to what consumer advocacy is all about. These issues and questions need to be rigorously debated, as there are diverse perspectives as to what work consumers could do within services, so as to develop a credible and sensible rationale for what consumer workers do and what they don't.

## **8 Many consumer advocate positions lack the necessary independence to fulfil the most basic principle of advocacy, ie, that it is autonomous and independent from service delivery.**

- A fundamental principle of advocacy is that it is independent. Most consumer advocates in NSW work within the same service that employs them. This is problematic because conflict of interest issues lead to a diminution in the quality of advocacy. I have identified a number of conflicts, such as where advocates choose not to pursue a legitimate advocacy issue for fear of rocking the boat, upsetting staff or managers, being

branded a trouble maker, or facing dismissal and therefore losing income. Another conflict occurs where employed advocates are used for all of the representation in the service, thereby blocking the pathways to more participation by other consumers, and to broader engagement. Pressure is being placed on some advocates to cease consultation, or to go along with things and not raise concerns – this pressure is sometimes directly explicit. Lack of capacity to make public comment means that much ‘consumer voice’ has been lost in the last decade. Advocates in theory ought not be engaged in service delivery in the same service that they provide advocacy. This keeps a healthy separation and reduces the softening of advocacy – a trend that can be noticed in some services, where advocacy barely occurs whilst softer things like running activities have asserted themselves.

I am left questioning whether consumers using services today generally have access to independent information and resources to assert their rights, or any quality consumer advocacy service. Where is the tsunami of change that I dreamt would sweep through services, led by consumer advocates and other change agents, to ensure that consumers are informed and enabled to assert their rights and to advocate on their own behalf? Tsunami, or a sea full of little tiddlers, swimming in the same direction as the service, part of the problem and no longer the solution.