

CONSUMER ADVOCACY - WORKING WITH SERVICE PROVIDERS

Introduction

B. Miles provides medium term supported accommodation to women without dependent children who have a mental illness. We are based in the Eastern Suburbs of Sydney and have the capacity to house up to 28 women. Women can stay with us for a maximum of 18 months.

Background

Prior to working at B. Miles I had not worked for a mental health service. My knowledge about mental health was minimal. However, I had worked in the welfare sector for about 15 years, so I had considerable experience in a range of areas, especially in relation to housing.

At first, I felt totally overwhelmed at B. Miles. I was really conscious of my lack of mental health knowledge and found conversations with some mental health staff from the local Health services to be really intimidating. They used words that I didn't understand and talked with such an air of authority that I was too embarrassed to ask what they meant. In time though, I realised that it was actually beneficial for B. Miles that I did not have a background in mental health. I was not jaded. I did not arrive with too many pre-conceived ideas about our tenants and what to expect. I was not cynical about the tenants. I was in many ways, a clean slate - ready to learn and open to new ideas. I was also willing to take risks and to make mistakes.

What is consumer participation?

In their publication *From Consumer to Citizen* The NSW Consumer Advocacy Group defines consumer participation as “a process to improve the quality of service delivery

and increase the level of consumer satisfaction with public mental health services.

Consumer participation in the mental health field means that the service providers ensure consumers have the opportunity to influence decision-making processes in the areas of service delivery, service planning and development, training and evaluation.”

(Shipp,1997, p.17)

Consumer participation is not a *feel good* notion. It is vitally important in enabling mental health services to be responsive to the needs of the consumer. It enables consumers to have a higher quality of service provision; to take responsibility and control over their lives; and can be empowering to both the consumer and the service provider. Consumer participation challenges the belief that the professionals know what is best for the consumer.

So important is consumer participation, that it has been included in the Nation Standards for Mental Health Services. *Standard 3 - Consumer and Carer Participation* states that consumers and carers are to be involved in the planning, implementation and evaluation of the Mental Health Service.(Commonwealth of Australia, 1997, Page 10). For Health funded mental health services to receive funding, they must show that they have adopted the National Standards. In other words, consumer participation within Health funded mental health services has been set in cement. It cannot be avoided.

Partnership

For consumer participation to be effective it must be based on partnership. Janet Meagher, in her book *Partnership or Pretence* says “Partnership is associating in a common endeavour, moving forward together through the process of learning about each others skills, knowledge, strengths, and abilities in mutual growth”. (Meagher, 1995,

Page 20) For partnership to work though, it is crucial that the consumer has a say in defining what that common endeavour is. Partnership is not genuine if the service providers do not involve consumers in the decision making process. In their paper '*Are you with us?*' *Working in partnership with mental health consumers - a consumer perspective* Kate Tarrant and Robyn Priest state "Surely mental health consumers, the ones who are ultimately affected by such decisions, should have a say in the services which, presumably, are there for them. This is the basis of the concept of partnership." (Tarrant & Priest, 1997, Page 256) They define the goals we should aim towards around partnership as being:

- ◆ " the involvement of consumers in planning, running and evaluating services;
- ◆ treatment which respects the individual and maintains their dignity;
- ◆ full information on treatment, rights and the options available;
- ◆ consumer employment through equal opportunity practices; and
- ◆ commitment and resources for 'real' consumer involvement." (Tarrant & Priest, 1997, Page 256)

Why is consumer participation and partnerships so important?

The answer to that question is very simple - consumer participation leads to changes in mental health systems and services and community attitudes. (Mental Health Branch, Commonwealth Department of Health and Community Services, 1999, Page 1) In Australia, consumer participation has had an enormous impact. It was due to the hard efforts of national non-Government organisations concerned with mental health (such as: the Australian National Association for Mental Health, Schizophrenia Foundation and GROW) that Federal policy makers had to begin to respond to concerns within the mental

health sector. (Mental Health Branch, Commonwealth Department of Health and Community Services, 1999, Page 10) These national organisations had strong consumer and carer representation. State based consumer and carer groups (e.g. Victoria ARAFEMI and the Schizophrenia Fellowship of Victoria) began to form in the 1970's. Collectively these groups have lobbied hard for changes to be made in our mental health system. Thanks to the hard work of consumers/carers and others, people living with a mental illness in Australia now have legally sanctioned rights.

Some History about Consumer Participation at B. Miles

When I started at B. Miles there were few opportunities for tenants to have a say. A tenant survey had been designed, but not distributed. There had been a tenant on the Management Committee who was the contact person for all tenants, but she had just resigned due to the stress that this job created. In fact, the women were not called tenants, they were called residents - a term I despise in the context of our service.

My introduction to consumer participation happened when I attended the 1997 THEMES Conference in Sydney. I went to a number of sessions that were run by consumers and became inspired by the whole concept of consumer participation and decided that it was high time B. Miles started to develop some of its own consumer participation opportunities. I came back to the office full of enthusiasm and energy - it was almost like I was 'born again'. I have to say, I remain just as excited about consumer participation today and just as convinced that it is a vital and integral part of the whole mental health system.

Consumer participation within B. Miles

As we are not Health funded, we are currently under no legal obligation to involve consumers in the planning, implementation and evaluation of our service. In time, I believe that this will change. However, we did not wait until we were forced to do something about consumer participation. Hearing consumers talk so passionately about the issue was enough for me to decide to take action. Plus, it made sense.

So, what have we done? Firstly, we believe that there is not one way to involve consumers. Consumers should be given a variety of opportunities to be involved. For example, some people do not like filling out surveys, but may be happy to come to a group meeting. Therefore, we have a range of consumer consultative mechanisms within B. Miles.

Payment to tenants

It is B. Miles policy that tenants are financially reimbursed when we involve them in consultations.

Annual Tenant Surveys

Firstly, I made sure that the tenant survey that had been lying dormant was sent out to everyone on an annual basis. To encourage tenants to respond we made sure the survey was easy to complete and ensured confidentiality. We also provided a self addressed stamped envelope so that there would be no cost associated with filling it out.

Subsequently, we have a very high return rate. For example, in 2001 17 women sent their completed forms back to us. The results are then sent out to every tenant and are written up in our Annual Report. The findings are discussed within staff and management meetings and when possible, acted on (not all suggestions can be adopted,

e.g. B. Miles to be staffed 7 days a week, 24 hours a day). The survey results are also used at our Annual Planning Day.

Moving Out Form

Upon leaving the Scheme, tenants are invited to complete a moving out form. This provides another opportunity to inform us as to what they liked about the Scheme, what they didn't like and suggestions for improvements. The results are collated on an annual basis and are distributed to staff and Management for discussion within meetings.

Whenever possible, suggestions are acted on. They are also incorporated into our Annual Planning Day.

Annual B. Miles Planning Days

Three tenants are asked to participate in the Annual Planning Day. The Planning Day is attended by staff, Management Committee and consumers and is run by an outside facilitator. We attempt to ensure that the tenants represent different age groups and cultural backgrounds within the Scheme. We decided to have three tenants for a couple of reasons. Firstly, we believe that no one person can represent a whole group. We also acknowledge that a planning day can be intimidating. Therefore, by having 3 tenants, there is not so much pressure on one person. We also hope to provide the opportunity for mutual support.

Consumer Consultative Meetings

I realised at the THEMES Conference, that it was vitally important for consumers to have the opportunity to meet to discuss their experiences within B. Miles and to inform us of their issues and suggestions for improvements. It was also clear to me that these meetings had to be a staff free zone. The framework for the meetings was developed in

consultation with two ex-tenants who had been trained as consumer advocates. The initial consumer consultative meeting was held at B. Miles, without staff present, and was run by the same two consumer advocates.

So successful was this initial effort, that I then got a student on placement (who happened to be an ex-tenant) and we tried to get funding for a permanent, part time, consumer advocate position within B. Miles. Inherent in this was further development of the model for consumer participation/consultation within the service.

This was when I discovered that consumer consultation was not a priority outside of mental health. We also discovered that Health was only interested in funding consumer activities within its own department. We tried to get funding from a number of sources, including: the NSW Premier's Department; the Casino funding; the NSW Department of Health; the Commonwealth Department of Health and Community Services etc etc.

We were not successful in obtaining funding. Rather than let this stop me, I decided to go ahead anyway. I then got another student and she worked with the 2 consumer advocates to set up another series of meetings with the tenants. This time, the group decided to meet at each others houses and that the meetings would be fortnightly. When one of the consumer advocates resigned, we replaced her with a tenant who had been trained as an advocate.

These meetings were very successful for a while. However, problems began to emerge. Conflicts arose within the group and these were very challenging for the advocates. Soon after, one of the advocates resigned and the group stopped meeting. The advocates and I then met to discuss what went wrong. The following was identified:

- ◆ B. Miles had not adequately resourced the advocates. They did not have job descriptions; there were no back up plans about what to do if participants were unwell; we had not planned for disputes erupting within the group; and we had no Occupational Health and Safety procedures in place.
- ◆ the group was meeting too often - some people were becoming too dominant in the group and this was causing friction to arise. Dynamics were starting to form with the 'regulars' and it was hard for new comers. The focus of the group changed - it became a support group.
- ◆ meeting in people's homes affected the power balance within the group. We realised that the meetings had to happen in neutral territory.
- ◆ the consumer advocates lost considerable support when the student placement finished.

Now we are trying again. This time round we are doing it differently. We intend to have 2 consumer consultative meetings a year. They will be held at a venue within the community, without staff present. Two consumer consultants will run the consultations. Prior to each consultation, the consumer advocates will meet with representatives from B. Miles to discuss the purpose of the consultation, promotion of the consultation to participants, Occupational Health and Safety issues etc. These meetings will also be used to clarify: the roles of everyone involved; who does what tasks; expectations etc. Tenants and ex-tenants (who are still connected to the service) will be invited to attend. The consumer advocates are also encouraged to meet separately to discuss how they intend to run the meeting. After the consultation, draft minutes will be sent to all tenants and selected ex-tenants, despite their attendance or non-attendance at the consultation, and

they will be invited to comment. Various options of doing this will be offered. A final report will then be written for B. Miles Management and staff.

Other

I also believe that the way we run B. Miles offers opportunities for tenants to have a say. At the point of assessment, it is acknowledged that the assessment is a two way process. We are assessing the client, and she is assessing us.

Tenants identify their own needs, goals and strategies. We respect that each woman knows what it is she wants to work on while at B. Miles. Our role is to support her in this and to assist her to achieve her goals. Tenants are able to change support workers if this relationship is not working for them. Tenants are also encouraged to come forward with any issues they may have about the Scheme and are given an absolute guarantee that they will not be evicted nor punished for being critical of us. In fact, significant changes have been made in the Scheme as a consequence of complaints.

Tenants decide whom they will live with within the Scheme. We do not move people into houses without involving the current tenant. House meetings are held to give tenants the opportunity to resolve issues that may emerge while living together.

B. Miles ensures that every tenant signs a lease and that we adhere to our legal responsibilities therein. That is, I can't just barge into a house to check if the housework is being done. Nor can I just throw someone out - I have to go through the Tenancy Tribunal.

We have developed a Tenant Handbook (it has just been re-written by an ex-tenant) so that tenants are fully informed about everything they need to know when they move in. The Handbook includes a list of Tenants Rights and Responsibilities, as well as

complaints procedures. Extensive consultation was carried out with tenants when developing the Handbook.

We consult with tenants when purchasing new furnishings for the properties - sometimes they will come shopping with us.

Importantly, the underlying philosophy of B. Miles is respectful of tenants and recognises the importance of tenant participation within the Scheme. We believe that each woman is the expert of her own life. That she has the capacity to make her own decisions and has the right to have these respected. However, we also have to balance this with what is good for everyone else within the Scheme. For example, if a woman is drinking excessively and is in a shared house, this can create problems for her housemate and possibly the neighbours. In this instance we have an obligation to intervene, as her choices are detrimental to others. This is probably the most difficult type of situation that we have to negotiate, that is, trying to be respectful of all players in a situation that is creating conflict and finding solutions that everyone is satisfied with. Sometimes we are simply not able to successfully achieve this. We are also bound by Duty of Care and have a legal obligation to intervene if a tenant is at risk of harming herself or at risk of harming others. We carefully evaluate this prior to acting.

We also do a lot of 'little' things that go a long way to making people feel comfortable and valued. Such as: welcoming women when they visit the office; taking a few minutes out to stop and talk to a tenant or ex-tenant if she is in the office; making the B. Miles lunches an important priority and valuing the time spent at lunches; having a laugh with the tenants; remembering details about their lives and talking about them with the women, e.g. asking how her children are going and showing a genuine interest in their

welfare; in other words, showing respect and concern for the women in our Scheme. We also try to be careful of the language we use. For example, you will not hear the term 'schizophrenic' being used by a staff member.

Barriers and pitfalls for Consumer Advocates

Being a consumer advocate is not always going to be easy. This work challenges existing structures and beliefs and this can create conflict - thus there will be times when advocates may question why they ever became involved in this type of work. Some of the barriers and pitfalls that may be encountered include:

- ◆ negative attitudes about the value and worth of consumer participation and advocacy - this can manifest itself in a variety of ways.
- ◆ tokenism - again there are a number of ways that consumer participation can be tokenistic. For example, I believe it was tokenistic of B. Miles to have a tenant on the Committee without providing her with adequate support. It was also tokenistic because it was the only mechanism by which tenants could have a say, outside of the complaints procedure. Further, the tenant representative was not paid for her work. Yet it 'looked good' that B. Miles had a tenant on the Committee. In reality, the tenant required hospitalisation due to the stress she experienced as the representative and she subsequently resigned from the position.
- ◆ it is difficult to represent a whole group of people. Every person is unique. Therefore, it is impossible to be able to speak on behalf of every person in Australia who has a mental health issue. It can be an easy trap to fall into.
- ◆ Advocates will not always be free to present their personal view, particularly if they are the nominated representatives of a group.

- ◆ communication is an essential element of the work. Effective communication is a skill, and one that takes time to develop
- ◆ confidentiality could become a problem if it routinely hinders consultation or is used to stifle discussion, or compromises an advocates independence
- ◆ sole consumer representatives may feel very isolated
- ◆ some advocates complain of being inadequately supported by the organisation they are representing
- ◆ there are legal liabilities for board or committee members
- ◆ there are costs associated with being a consumer advocate - phone calls, child care, transport, time away from work etc.
- ◆ stigma - unfortunately this is still alive and well in our community. There are undoubtedly risks in 'coming out'.
- ◆ role strain - e.g. some advocates have been on the same committee as their treating doctor
- ◆ resistance to change - some systems are simply very difficult to change, in particular, those that are based on the 'medical model', i.e. most hospital environments. These systems are based on very rigid hierarchical structures and can be very hard to influence
- ◆ stress - for some, the stress may trigger a relapse. In some work environments this may cause problems. There may be resentments from other staff about the amount of time an advocate has off work, and the subsequent impact on their workload.
Advocates may feel uncomfortable about their work peers knowing that they have had a relapse etc.

- ◆ conflict of interest - e.g. an advocate is on the selection panel for the new consumer advocate position, when they look at the applications, a really close friend of theirs has applied for the job.
- ◆ confronting change - all advocacy work causes people to confront change - both at a personal level and an organisational level. Advocates have to deal with a variety of responses to change, ranging from total resistance through to differing levels of acceptance.
- ◆ high self-expectations - advocates may become disillusioned if change is slow to happen and therefore blame themselves. (References for this section were drawn from: Commonwealth Department of Health and Family Services, 1999; Tarrant & Priest, 1997; Consumers' Health Forum Health Forum of Australia, 2000)

Overcoming barriers

Firstly, identify the barrier(s). Then develop plans and strategies to overcome them.

Start with the ones that you think are easiest to overcome. Work on one barrier at a time.

“The following ideas may be useful:

- ◆ Define and describe the barrier;
- ◆ Describe the problems that result from the barrier;
- ◆ Describe who or what benefits from the barrier;
- ◆ Generate possible solutions for the barrier.” (Commonwealth Department of Health and Family Services, 1999, Page 82)

Working effectively with service providers

Firstly, it must be acknowledged that there is a range of ways that consumers and carers can participate. I am not going to define them here, as this is a paper unto itself. For

more reading on this I recommend *The Kit, A Guide to the advocacy we choose to do* and *Improving Health services through consumer participation* which is produced by the Department of Health, Flinders University and the South Australian Community Health Research Unit, in particular Section 3 - The Tools Catalogue.

A few tips on working effectively with service providers:

- talk with other consumer advocates and find out what their experiences have been like, find out the good and the bad;
- be clear within yourself about what it is you are doing and why you are doing it;
- be mindful of who you are representing and seek input from other consumers;
- be fully informed about your role - make sure you feel that you can achieve the requirements of the job description. If there are any areas that you lack confidence in, find out if there are any opportunities for further training;
- find out what expectations others are placing on you, are they realistic? Also, what expectations have you placed on yourself - are **they** realistic?
- develop effective communication skills (this is a topic all of its own too). Just a hint, aggressive communication is usually not very effective. To quote Janet Meagher “Work with, not against service providers and carers and remember real ‘strength is in gentleness’ (Roman Proverb).” (Meagher, 1995, Page 54)
- Be consistent and persistent, do not give up. Repeat the messages over and over again. It takes some people longer than others to get the point. It helps if you can also be patient. Unfortunately, some people will never get the point.
- Find a mentor, someone who you can draw guidance from and who can support you through the more challenging times.

- Peer support is also important, don't just rely on your mentor. Seek out other consumer advocates for information exchange; mutual support; guidance etc.
- Networking is crucial. Do not limit this to other consumer advocates. There are lots of really good people involved at all different levels within the mental health sector.
- Obtain debriefing. If you have been involved in something that affects you on a personal level, it is really important to have the opportunity to de-brief with someone who has the skills to do this and who you trust.
- Devote time to self-care. Find ways to reduce your stress levels.
- Acknowledge your successes. In Australia it is common to put ourselves down for fear of being considered full of ourselves. If you do not acknowledge the good work you have done, you will probably burn out. Don't be frightened of saying to yourself that it was a job well done.
- On the other hand, don't be frightened of making mistakes. Use the knowledge you gain from this to improve on your own practice. Again, ongoing training will complement the lessons you learn from your own experience.
- to quote Janet Meagher again "Be flexible, not pig-headed, but be strong when you must be". (Meagher, 1995, Page 54)

"The Kit, A Guide to the advocacy that we choose to do" has a list of suggested strategies to enable consumer advocates to gain support from service providers.

Conclusion

I would like to acknowledge the lessons I have learnt from consumers I have met along the way over the last 6 years. I thank all those consumers who have shared their

knowledge and skills so that I can better manage the B. Miles Women's Housing Scheme. Thank you also for allowing me to make the mistakes that I have and for forgiving me afterwards. B. Miles is a much better place as a result of the input we have had from our consumers.

This paper was originally written for presentation at a consumer workshop in May 2002. It has been modified for the purpose of publication on the B. Miles website.

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