

# Exploring the Expression of Personal History within Consumer-Centred Teaching

MARK LOUGHHEAD

Over the last ten years, the area of mental health care has seen the gradual evolution of professional development practices that involve consumers and carers as key teachers. In acknowledging the development of the consumer movement, it is now relatively common for mental health services as well as teaching organisations to invite or employ consumers (in particular) to become teaching partners in aspects of professional education. This article looks at the issues surrounding consumers and carers using their personal stories in the teaching context.



The development of consumer/carer teaching positions in a number of Victorian universities reflects a movement towards greater inclusion of consumer and carer perspectives in the learning experience (Happell & Roper 2002). Strategies range from invitations to deliver one-off presentations to having more extensive employment-based participation within a program.

This type of participation in teaching is a highly valuable project. The existing literature in the field highlights the depth of learning and communication that can occur when education is linked to personal and lived experience rather than to abstracted models and theories of practice (Felton & Stickley 2004; Frisby 2001; Reynolds & Read 1999). There is a greater possibility for studying professionals to understand recovery approaches to health care, as well the broader themes of acknowledging the whole person, supporting identity, improving inclusion and open communication (Deakin Human Services Australia 1999;

Frisby 2001). Additionally, participation in teaching also enables or encourages a conversation about the themes of justice and historical injustice between consumers, carers, service providers and the wider community (Felton & Stickley 2004).

In this study, undertaken as my PhD research, I sought to develop an understanding of the types of roles that consumer and carer advocates play in the educational environment with mental health workers (I use the term 'advocates' to refer to consumers and carers who have become significantly involved in activities within the mental health sector). I also explored the areas of knowledge, experience and networking advocates utilised in providing learning opportunities. The approach was interpretive, ethnographic research that involved periods of field work with consumers, carers and professional educators in transcultural mental health. Interviews, conversations and observing teaching sessions were the main methods used.

It is important to acknowledge at this stage that I am writing not as a mental health consumer or carer, but rather as a professional person who has a commitment to advancing the inclusion of consumer/carer perspectives in teaching practice and general decision making in health care. Consumer and carer readers may be wary about how I have interpreted the experiences of advocates during the study and in this article. In response to this, I encourage readers to read the article from a critical viewpoint. The positioning I took in undertaking the study was not to tell the truth about consumer/carer experiences of teaching practice, but to highlight general trends and observations that may further the ways in which organisations support and partner with advocates in this role.

This article reports on a section of the study that focused on advocate's expression of personal history in their participation. Throughout the study, I became increasingly interested in the dynamics by which consumer/carer advocates chose to reveal their personal history within public contexts. I found that the connections between the 'private' and the 'public' were expressed on many levels and across different issues, with some issues deriving from the 'storytelling' expectations of the consumer movement, and others from consumer fears of exposure to stigmatising attitudes (Sozomenou et al. 1999). In teaching work, the private-public connection was a central feature where consumers and carers told their personal story as an educational method. For some advocates, the personal story was a powerful way of illustrating issues, of portraying injustice and a common humanity. For others the personal story was important, but not the only source of knowledge able to represent consumer and carer interests.

### Themes Arising from the Study

In a sociological sense, the research generated five critical themes for understanding the 'cultural' dynamics of how consumers, carers and professionals experience the 'personal in public'. These were:

- ← how teaching organisations value personal experience;
- ← the impact of personal stories—potential for changing attitudes/practice;
- ← understanding the costs of exposure;
- ← speaking from the sick role; and
- ← managing disclosure and personal distance in teaching.

### How Lived Experience is Valued by Organisations

As the need to value lived experience has gained momentum and become a feature of the policy environment in mental health care, there also arises a need for organisations to practice (and value) this idea as an 'organisational outcome'. While most genuine and successful projects are dependent on this support, many consumers and workers would also recognise this theme in terms of token practices of involvement, where participation is more influenced by the need to 'sign off' on the area, rather than having a genuine level of partnership.

On another level however, there is also the feature that advocates become involved via trading on their personal experience as a consumer. As job specifications are written for consumer consultants, expectations are developed for a group of employees who have to perform work which is tied to personal history. There is also a sense that advocates and consultants will need to utilise their knowledge and personal stories at times to perform their work duties.

This feature of participation is mostly apparent for consumers who become employed within services, but also exists where organisations 'need' consumer representatives to speak on a particular issue. Interviewing and recruiting practices are common situations where consumers and carers may first experience the need to identify aspects of their personal history and health status for their work. Once in the role of consumer or carer advocate, there can be many opportunities for personal questions or invitations to speak publicly at professional development sessions.

Roper (2003) has pointed out that particular occupational health and safety issues are present for employed representatives and advocates. There is a close connection between personal identity and work performance that is quite different to the cultural expectations which clinicians may be expected to work within. The job title for professionals does not reveal a part of their health identity nor place expectations of disclosure when utilising knowledge and skills. This theme connects with Church's analysis (1995) on relations between consumers and providers. In her view the personal sharing and disclosure characterising the consumer movement "clash awkwardly" (p. 66) with the managed persona of professionals and the culture of services where participation is often structured.

While consumers have built the movement via intimacy and sharing experiences of the system, mental health providers:

*"...operate in the mental health field under exactly the opposite requirement. Professionalism is orientated towards objectivity, making judgments and decisions which are not 'coloured' by feelings, separating the private aspects of life from the public" (p. 66).*

### The Impact of Personal Stories

Many consumers and carers want to change the system and help to shift various discriminatory profession attitudes. In speaking about their experiences of mental health care, the personal story is a natural way of expressing their own 'truths' and those relayed by other consumers. Additionally, advocates sense that stories have power in appealing to the emotional selves of audience members. Many participants spoke to me about using their personal stories to get professionals to feel or imagine the experience of mental illness. Advocates would often point out to audiences that the characters of particular stories could also 'be you', 'or your parents, partners and children'. From this angle, advocate/educators could also then talk about the negative impact of assessment and treatments processes which had identity shaping outcomes for consumers and carers

(see Coleman [2000] for his analysis on the effects of chronicity).

Thus, an important realisation for me was that advocates use their own stories to help professionals to reconnect to their own 'consumer identity'. Whereas professional, organisational culture ensures that practitioners have some distance from the personal/emotional experience of helping in mental health care, advocates actively encourage audiences to reconnect and evaluate their practice from this viewpoint.

## Understanding the Costs of Exposure

Given the historical context of institutional care and discriminatory attitudes to mental illness, the job of reiterating the shared life-world between consumers, professionals and the wider community is likely to come at a cost. From this perspective, it was interesting to hear from participants about the negative potential of using personal stories. One participant relayed part of her experience of being asked to 'do a personal story' within workshops for general health staff:

*"They'll ask me to come in once a fortnight and give my personal perspective in general worker training and I talk about police officers and ambulance people and what happens when a person is psychotic and aggressive with you. How you should gain rapport. I talk a lot about communication skills and calming somebody down. But it's very much like putting myself almost on the chopping block. Like even though I still feel that's OK, because I'm distanced from it. Sometimes I think, you know? This is like an exciting movie to people, in the sense that I still don't think consumers have been educated enough, including me, on what are the boundaries of what we should say about our personal lives. Because people are almost like, vultures seems a strong word. But this is a metaphor".*

This participant's experience of personal storytelling was that it was a very powerful and effective method of shifting attitude. However, she was quite worried about the ongoing effects of this for her own health and identity. Her views connected with a number of participants who raised concerns about the 'voyeuristic' nature of public speaking where audiences are not able to reciprocate in the same way. In this sense, using the personal story often occurs as a one-way disclosure. As another participant noted:

*"I'm packing shit half the time because there's a room of 50 people who I don't know from a bar of soap, having to divulge my deepest secrets. So (the story is) a very tall order".*

Many advocates pointed out the excellent support they receive from other advocates and workers during these instances and also the liberating experience that can follow their work. I was also struck by the tremendous skills of experienced advocates in public speaking and utilising storytelling to get key messages across to audiences. They were very comfortable in their work and seemed to be able to cover the inherent vulnerabilities of the role. While this was the case, I wondered about those advocates

new to the field or those that preferred not to utilise personal history in their teaching work.

## Speaking from the Sick Role

Sociologists have noted that the personal health struggle is a powerful cultural narrative for communicating a sense of western individuality (Frank 1998; Crossley 1999). Stories of recovery or restitution are important reminders of capacity and spirit—they carry possibility as well as share important wisdom to audiences. One of the interesting points made by one study participant on this topic is that audience expectations are a part of this narrative form. These also significantly influence the position of the speaker. In terms of her experience this participant argued that audiences:

*"Can't help wanting the presenter as a sick person, but they also want a well person to talk about a sick person. They want me to talk about my illness, present myself as sick".*

This comment here highlights a juxtaposition underlying storytelling. Advocates speak from a position of wellness on their story of being unwell and making the journey to wellness. Whilst this is an important feature of the consumer movement—this participant went on to argue—the approach does not necessarily articulate the kind of messages that many consumers want to convey. The well/unwell/well positioning tends to "keep me in the sick role where you can manage me".

For this advocate, consumer-led teaching is a much broader role than the experience of illness in that many consumer issues are more related to human rights and power imbalances with service providers and the wider community. Issues relating to the experience of services and treatment can, of course, be told via personal stories, but these are also observable features of the current system. In this later sense, consumers can engage in teaching by opening contemporary debates on standards of care, legally enforced treatment, the reliability of diagnostic practices and the access of consumers to mental health advocates. It should also be noted that during the study, many professionals also pointed out concerns about the negative possibilities associated with using the personal story in a teaching context.

## Managing Disclosure and Personal Distance in Teaching

Some advocates suggest that the popularity of consumer storytelling within the mental health sector can be a limiting form of participation. This may be one reason why the broader term of consumer perspectives is becoming the preferred way of framing consumer input in teaching practice. This term covers a range of value positions and common analysis provided by consumers in the contemporary movement (Epstein & Olsen 1999).

In this respect, many advocates in the study pointed out that teaching experience was a journey in gaining the knowledge, skills and confidence to teaching about consumer/carer perspectives. On the level of knowledge, advocates utilised their

historical knowledge of consumer issues as well as current networks to develop a general analysis from which to base their teaching. This also included knowledge from policy reports, consumer publications and newsletters, and professionally developed ideas. In terms of skills, many advocates spoke on learning new approaches and methods for delivering training. These included presentation and facilitation skills as well as exercises such as brainstorming and small-group work. Confidence related to experience in teaching roles, the availability of support from other educators, the sense of being a part of the teaching team, and debriefing and learning opportunities.

As my learning in this area progressed, I came to see that advocates utilise various techniques and approaches that position them as an educators in relation to students and audiences. Formally having this status, and being seen as a legitimate teacher by peers and students, helps advocates to speak from a position which is quite different to being a 'speaker from experience'. On one level, it helps to open possibilities to how advocates will communicate their key messages and encourage students to understand consumer/carer perspectives and recommended change to practice. On another, it also enables advocates to have space and distance around the need to reveal aspects of their own history. They are able to utilise their own story in preferable ways or when they feel it would have the most impact on audience members. Or they may choose not to use it at all.

## Conclusion

One of the central themes of this last section is that it encourages advocates to consider their own involvement in teaching practice and the various ways in which they can locate and express personal history to professional audiences. This is an important point not only for advocates but also for teaching organisations and supportive team members. Employers and professionals undertaking participation-based teaching are invited to consider the various expectations in which community members are invited to share their knowledge and experience. Given the potential vulnerability of speaking from experience, especially as a regular and 'performed' practice, it is important that all partners encourage flexibility and diversity in ways in which consumers and carers inform an organisation's teaching.

A key learning from my study was that a deeper level of involvement, where consumers and carers are employed as an ongoing part of the teaching team, assists advocates to develop the skills, knowledge and confidence to participate effectively in this arena. This level of involvement acknowledges the safety issues involved for advocates and provides a supportive

environment for learning. It also acknowledges that consumer and carer perspectives need to be integrated as a standard and organised part of the curriculum in contemporary professional development.

*Mark Loughhead is a social worker who has worked in the area of multicultural mental health for many years. Mark currently works for the University of South Australia as a research assistant and casual lecturer. He is also a project officer with the Health Consumers Alliance of South Australia. If you would like a PDF (electronic file) version of the study (a thesis), please email him at [Mark.Loughhead@unisa.edu.au](mailto:Mark.Loughhead@unisa.edu.au)*

## References

- Church, K. 1995, *Forbidden Narratives: Critical Autobiography as Social Science*, Gordon and Breach Publishers, Newark, NJ.
- Coleman, R. 2000, 'The politics of the illness', in Barker, P. and Stevenson, C. (eds.), *The Construction of Power and Authority in Psychiatry*, Butterworth Heinemann, Oxford.
- Crossley, M. 1999, 'Stories of illness and trauma survival: Liberation or repression?' *Social Science and Medicine*, Vol. 48, pp. 1685–1695.
- Deakin Human Services Australia 1999, *Learning Together: Education and Training Partnerships in Mental Health*, Commonwealth Department of Health and Aged Care, Canberra,
- Epstein, M. & Olsen, A. 1999, 'An introduction to consumer politics', in Clinton, M. & Nelson, S. (eds.), *Advanced Practice in Mental Health Nursing*, Blackwell Science, Oxford.
- Felton, A. & Stickley, T. 2004, 'Pedagogy, power and service user involvement', *Journal of Psychiatric and Mental Health Nursing*, Vol. 11, pp. 89–98.
- Frank, A. 1998, 'Just listening: Narrative and deep illness', *Families, Systems and Health*, Vol. 16, No. 3, pp. 197–212.
- Frisby, R. 2001, 'User involvement in mental health branch education: Client review presentations', *Nurse Education Today*, Vol. 21, pp. 663–669.
- Happell, B. & Roper, C. 2002, 'Promoting consumer participation through the implementation of a consumer academic position', *Nurse Education in Practice*, Vol. 2, pp. 73–79.
- Roper, C. 2003, 'Consumer perspective employment in the psychiatric service system: A Victorian view on safety issues', *Australian e-Journal for the Advancement of Mental Health*, Vol. 2, No. 1, pp. 1–2. Retrieved 26 June 2003 from [www.auseinet.com/journal](http://www.auseinet.com/journal).
- Sozomenou, A., Mitchell, P., Fitzgerald, M.H., Malak, A. & Silove, D. 1999, *Mental Health Consumer Participation in a Culturally Diverse Society*, Australian Transcultural Mental Health Network, Melbourne.
- Reynolds, J. & Read, J. 1999, 'Opening minds: user involvement in the production of learning materials on mental health and distress', *Social Work Education*, Vol. 18, No. 4, pp. 417–431.