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Walls of Jericho – Trumpets and Partnerships

Firstly, I would like to apologise for not being present to deliver this paper as I would have loved to do.

As is especially clear in the world that we live in at present, it is very easy for people to come to conclusions which establish set positions and offer no hope for any real advancement, change or indeed at present even peace. War is the only resolution to the problem at hand and the only solution contemplated as possible. We cannot ever trust the enemy, what they say, what they promise or what is offered. It appears that the only way to breach the Walls of Jericho is to blast them down with war trumpets and strength of arms and remove the barriers.

But I ask you to consider what wall you have ever seen that does not have a gate in it through which we can all pass. The Berlin Wall had gates, even the Great Wall of China had gates. We do not need to blast the walls to meet and come to mutual agreement we merely need to open the gate with the intention of reaching agreement.

I would not suggest that the Clinical Practice Guideline project was as extreme as that, nor that war was ever possible but there were difficult issues to transcend.

At one point we all sat around a table, members of our four committees, consumers, carers, mental health workers and mental health researchers, and we discussed the thorny issues of partnership, confidentiality and consumer empowerment.

These issues have evoked heated debate in the past and I am sure that they will in the future. In the past angry words have been said about rights, both consumer and carer rights, about exclusion from the processes, about lack of information and failure to be involved, and about medico legal risks. Discussion has occurred from set positions, with missiles tossed backwards and forwards over the wall, and these positions have been hard to shift.

During the clinical practice guideline process it was different. The discussion revolved around optimising outcomes for all parties.

Consumers spoke of the need for carers to have access to some information about them and about the important role of mental health workers. Carers spoke of the importance of consumer rights and confidentiality and how to ensure that consumers received these rights, and the importance of partnerships with consumers and mental health workers.

Mental health workers spoke of the need for transparency and the value of involving all parties.

All spoke of the failures of the past, their experiences within that failure and the need to do it better in the future.

The gates were thrown open with all intent on finding common ground, a mutually agreed solution that took all parties needs into account. The clinical practice project and the processes involved have the potential to change systems and the relationships that exist within those systems and to establish better ways of doing things. The development of real partnerships that consider the position and circumstances of each of the members of the

partnership has the potential to improve outcomes for all parties involved in mental illness, the consumer, the carer, the mental health worker and ultimately government and the taxpayer.

What is the project of which I am speaking?

Simply, it is the Schizophrenias: Evidence Based Best Practice Guidelines for the Treatment of Schizophrenia that was commissioned by the NSW Department of Health. As it developed I can say honestly that it was a large and sometimes terrifyingly large, project.

The overall objective of the project was:

To achieve better health and lifestyle outcomes for people with schizophrenia and their families or other carers by improving the practice of health professionals, and by better informing consumers and carers about the options available to them.

The guidelines cover a person with schizophrenia from the first emergence of symptoms to death. As noted before, they cover the areas of partnership, confidentiality and consumer empowerment as well as other areas such as:

- Assessment;
- Medication;
- ECT;
- Dental Care;
- Leisure;
- Diet;
- Accommodation;
- Homelessness; and
- Psychosocial Rehabilitation.

So what was different about our project? Why did we get so excited about what we were doing? And we did get excited - I couldn't get our committee members to stop for morning tea or lunch, I couldn't get them to leave at the end of the meeting. Unlike many other committees, we regularly had 100% attendance from the consumer and carer members and often close to 100% attendance from the mental health workers and researchers. People wanted to attend; they wanted to be involved.

A major difference between our project and other such "Best Practice" projects was the inclusive nature of it. Our bid to the NSW Department of Health specified the strong involvement of all key stakeholders and this was our cornerstone for the whole project.

To achieve this we established five committees:

- Management Committee;
- Consumer Committee;
- Carer Committee;
- Mental Health Worker Committee; and
- Research Committee.

The Management Committee consisted of:

- The President of the SFNSW;
- The Chairperson of each of the other committees;
- A representative from the NSW Centre for Mental Health;
- The Project Officer, Anna Tampke; and,

- The executive Officer of the SFNSW.

The Management Committee was responsible for the overall management of the project and met monthly. It kept us on track and all members had a very high level of experience and expertise.

The remaining committees all had 10 members each.

The Consumer Committee members were nominated by organisations such as the SFNSW, NSW Consumer Advisory Group, Mental Health Co-ordinating Council and the Australian Mental Health Consumer Network. Amongst the membership were people with non-English speaking background, Aboriginal background, rural and metropolitan background. **Further, this committee had amongst its representatives the President of the Australian Mental Health Consumer Network and three other persons who were working within the mental health services.**

The Carer Committee members were nominated by organisations providing carer support such as SFNSW, ARAFMI and NOUS, the Greek-speaking support group. Once again the membership reflected the diversity of our community with representation from NESB, Aboriginality, rural and metropolitan. **This committee had amongst its members an ex-Attorney General, two university lecturers and a retired high school principal**

The Clinical and Research Committees had representation from the five main areas of mental health professionals. Invitations were sent to the following to nominate a person for each committee:

- Australian College of Occupational Therapists;
- Australian Association of Social Workers;
- Australian New Zealand College of Mental Health Nurses;
- Australian Psychological Association; and
- Australian New Zealand College of Psychiatrists.
- A number of further invitations were issued to people identified as having special expertise or knowledge.

These committees met every four to six weeks and met on consecutive days when required. All committees met on the same day and met both separately and together, thus allowing the perspective of each committee to be established, then openly discussed to reach consensus. The gates were open from the start of the process.

The role of these committees became all encompassing; they were involved in every aspect of the project. **The stated roles were:**

- Decide what needs to be included in the guidelines;
- Review the text and specific guidelines;
- Come to a consensus, or non consensus for each guideline; and
- Rate the level of evidence to be assigned to each guideline.

It should be noted that each committee had an equal say in all aspects of the process.

We developed a process of reviewing the literature in a specified area, then preparing a paper for the committees which included summaries of the research literature and proposed guidelines, fully and openly discussing the paper and then amending or rewriting the paper for further consideration. Quite rightly, the committees could be quite brutal and some papers required complete re writing.

To further ensure the veracity of our findings we engaged a consultant to undertake two rounds of focus groups.

These focus groups covered four main key stakeholder groups:

- Consumer Focus Group;
- Carer Focus Group;
- Mental Health Workers Focus group; and
- General Practitioners Focus Group.

The aims of the focus groups were:

- To broaden the base from which the guidelines were developed. It is important that such guidelines are strongly derived from the community in which they will be used. And
- To act as a "check point" to ensure that what the four committees had developed was reflected in the wider community and to assess if any important areas had been overlooked.
- In the first round of focus groups we aimed to have 15 persons at each and came close to this figure with all groups except the general practitioner group. With regard to the carer and consumer groups, our target was the average consumer and carer. We were keen to get a true grass roots response.
- The mental health worker focus group was arrived at by inviting representatives from different area health services, with a spread of the various professions involved and an equal mix of hospital and community staff.

During the course of the project, over 200 people were directly involved and as the word spread we were approached by more people wanting to be involved. Members of the committees kept coming forward and volunteering to do more. It was impressive the extra effort people were willing, no demanding, to make.

Members of all committees assisted with the research, reading the mass of literature and writing papers for committee consideration. Members also volunteered their personal contacts outside the mental health field to assist the process.

It was impressive, and I believe instructive, how the atmosphere of collaboration and partnership developed. As I mentioned at the start, what could potentially be full on confrontation became optimisation for all parties.

Possibly the most vexatious area was that of confidentiality. Instead of a situation of carers demanding what they wanted, consumers saying that they couldn't have it and mental health workers saying that they couldn't give it, we have had open and frank discussions that looked at why do you want it, why giving it may be difficult and how it could be achieved. Carers became advocates for the consumer position, consumers for the carer position and mental health workers using their expertise to find solutions.

I am confident that we ended with workable solutions that will satisfy all parties.

There are two other important considerations that I would like to mention before finishing. Firstly, there is a risk that whenever something is codified, there is no flexibility and no chance to innovate. This should not be the case with these guidelines. They will need

constant upgrading and review. They should hopefully encourage innovation in areas where evidence exists and should promote exploration where suggestions are good.

The second consideration is implementation. We do not want to produce yet another dust gatherer for peoples' bookshelves. This document must be used if it is to have the impact that is desirable. We held a brainstorming session involving all members of the committees and have come up with a number of tactics for implementation.

We looked at how to make the documents easier to use and accessible to their respective audiences. For example, with the proposed general practitioner publication, we consulted with both those who attended the focus group and the NSW Division of General Practice and came up with an idea that came from those who will use it.

Possibly the most critical factor in implementation and operationalising the guidelines will be the sense of ownership that various groups feel they have over the documents. Our inclusive approach has already resulted in over 200 persons feeling that ownership. Two hundred people who believe in the project and will be part of the implementation process.

That's 200 people who are carers, consumers, mental health nurses, social workers, psychiatrists, psychologists, occupational therapists, general practitioners, government service, non government service, non English speaking background, aboriginal, metropolitan, rural and Mental Health Branch.

The trumpets of war can be turned to beautiful instruments of celebration and construction and the walls can be breached by either knocking at the door or being invited in.

The guidelines should be available in the near future, so watch out for them and watch out for the opportunity to go through the gates and join the partnership.

Thankyou.