

1.

Bridging the gap: Conversations about mental illness experiences

by

Gaye Stockell & Marilyn O'Neill

314 Nicholson St, Crows Nest NSW 2065, Australia
ph: (61-2) 9966 5966, fax: (61-2) 9966 0618

Over the years in which we have worked within community mental health services, we have had the privilege to hear many stories from people about their experiences of psychosis and their encounters with the services established to assist them. Many of these people have spoken of their own journey with particular purpose - to enable others to come to know what is useful and not useful in relation to responding to mental illness in the hope that more helpful approaches can be generated. Many of the people who have shared their ideas with us have also hoped that their experience would be understood and

appreciated differently to the way they found it was commonly viewed.

Not only have the ideas of the many people who have talked with us about these issues inspired our work with others, they have also been personally encouraging. It has become possible together to develop different, more helpful and enabling views of the experience of mental illness. This has challenged the traditional practices that we are often trained to work with and has resulted in the evolution of a never ending position of questioning that regularly informs our conversations with other workers in health and community services.

Today we wish to speak of the ideas of just one collection of people with whom we have been able to consult. The 'Bridging the Gap' Project was initiated by the Northern Sydney Community Mental Health Services¹ and involved consultations with people with experiences of mental illness, their families, workers in the mental health services and service managers. The idea of the project was to conduct a collaborative / narrative / co-research conversation with the people involved in the provision and utilisation of a large mental health service. The idea was very appealing to us as it was a chance to formally gather together some of the wisdoms about mental illness we knew these people had, and to circulate them amongst those we talked with as well as to a wider audience.

Establishing the project

To establish the project, we thought it was important to invite all parties to participate, that is, those people who have had and continue to have the direct experience of mental illness; families and friends associated with them; mental health workers and service managers. We also believed that using a narrative approach as the consultative process would enable us to engage in conversations that would:

- assist in separating problems from people, and work together at exploring dilemmas;
- uncover positive information about useful ways of viewing and dealing with dilemmas, especially when an overwhelming negative experience has meant those alternatives have been overlooked;
- take a political position that would validate individual experiences and

provide an understanding of the powerful forces operating in people's lives;

- acknowledge the importance of context and connectedness;
- offer the possibility of discovering directions people prefer for their lives and relationships.

Planning consultations

The initial part of the project was to establish the consultative process and an accountability mechanism for that process. We invited representatives from each of the nominated consultative groups to attend discussions aimed at exploring everyone's hopes for the project.

At the first meeting we met up with people who have had the direct experience of mental illness and members of their family. We introduced the ideas incorporated in narrative approaches to conversations. We spoke about David Epston's ideas on co-research and invited the participants to give their thoughts and opinions.

Curiosity and enthusiasm for working in partnership were apparent. Participants identified a number of difficulties they had personally experienced in previous interactions. Hopes emerged for a collaborative exploration that would allow us to work together exploring the unique and common difficulties experienced.

The metaphor of 'the gap'

In these initial consultations, one participant introduced the metaphor of 'the gap'. She explained 'the gap' as something that occurs as a result of differing perspectives. She said that, when an event occurs as a result of mental illness, each concerned witness to that event becomes like a 'mirror'. The 'mirror' is placed at a certain angle and then reflects particular aspects of the event. Each person knows their reflection is the correct one because it is in their mirror. However, each reflection presents a slightly different angle on the event and it is possible from each angle to construe different meanings.

These metaphors represented for the group an understanding of people's differing perspectives on the same event. The group thought people often relied on the one interpretation of the experience to the exclusion of other reflections.

This raised questions such as: What other interpretations might be possible if the mirrors were all used in the process of developing a more complete picture?

The group encouraged us to embark on the project. They were keen to have the ideas of all groups, including workers and management, gathered and cross-fertilised as a basis for future co-operative action. Their ideas and questions were taken as a guide for further collaborative consultations. Our hopes were to include the perspectives of all parties.

We decided to call this project: 'Bridging the Gap'.

PROJECT CONSULTATIONS

Individual consultations

Three people who experienced mental illness and who had heard about the project offered to contribute their ideas. Their contributions were extremely valuable.

Raymond², a member of the rehabilitation service, gave us feedback on the positive effects narrative conversations have had on his life. He said that this style of conversation had allowed him to shift his relationship with his illness. He said that after these conversations 'the illness started to take care of itself'. He could 'treat it just as any other illness', and he was then 'free to do ordinary things like getting enough sleep, learning to do what worked best' and 'dealing with the problem of carrying tension'. Raymond told us the technique of the narrative conversations had allowed him to name problems and separate them from himself. This had freed his thinking and actions so that he was no longer immobilised.

Alan³ raised with us the dilemmas of not knowing about members' experience of the service and how various decisions were made. The practices occurring in hospitals were of serious concern to Alan. He was particularly troubled by his observations that the least experienced medical practitioners were often the ones given the care of the people most troubled by mental illness. He also believed that the most experienced dealt with the least troubled. Alan believed that in pooling his thoughts with others who have had experiences of mental illness, and then pooling that expertise with workers, we

might develop some useful ideas.

A third consultation with Tony⁴ highlighted dilemmas arising from ‘being told what to do’. Tony related his experience of his time in a residential setting and of the experiences of his friends who were still living in that setting. He believed support was important but he had developed ideas about what was and wasn’t helpful. He said it wasn’t useful to be told ‘how to live your life’, the ways ‘you should do this’. He said it was useful to be consulted and supported in relation to your own ideas about what was good for you. He recognised the practical difficulties this might impose on workers, but felt strongly that it was an important consideration for rehabilitation and human rights.

Family consultations

Other consultations for the project took place with five families. The focus of these meetings was the ways in which family members were recognising the effects that mental illness was having on their lives, their relationships with others and with the wider community. The discussions in all families generated a greater understanding and appreciation of working together. Families spoke of how the experience of ‘being on the same team’ allowed their dilemmas to be dealt with. These family meetings gave all of us a sense of being a participant in a bridging of ‘the Gap’. Family members spoke of how the conversations enabled them to see difficult situations from other angles.

Worker consultations

The next phase of the project involved responding to an invitation from one of the teams of workers to join in an exploration of some of the difficulties they were having with their work. Team members nominated ‘busyness’ as a shared problem. Busyness was seen by them as having a major influence on their work practices. Although some saw busyness as giving them a sense of competence in crisis for the most part, it was recognised as establishing a

culture of 'fire fighting'. It invited 'an anxious view of clients as unmade beds' and encouraged workers, regardless of profession, to develop 'a super-nurse syndrome'.

The team identified that the problems they experienced were related to gaps between rhetoric and reality. They spoke of perceived expectations held by management, versus everyday possibilities and the difference between their expectations as workers and the expectations of those people who accessed their services. The team considered how they might prevent busyness from robbing them of the opportunity for helpful reflections on their work. We evolved the following questions for consideration:

- How might we convey the dilemmas and richness of our work and break from the isolation that lack of understanding often creates?
- How might we convey the nature of the work to management in ways that might address the restraints of upward accountability?
- How do we do justice to the team's ideas and 'not just mutter on'?

A second consultation with workers took place with the rehabilitation service. They also wanted to address dilemmas related to their work practices and to explore the gaps created between people in the psychiatric arena. They said the gaps often related to the differing expectations people had, and the varying values sometimes given to, different aspects of the service. They recognised, however, the significance for them, as a team, of having together embraced a narrative approach to their work. It had opened up possibilities of more clearly naming and dealing with the concerns people have with mental illness.

Using the narrative process, the team generated a number of questions that related to traditional recreation activities and rehabilitation programs:

- Whose purposes do these activities mostly serve?
- What meaning does an everyday activity have for a person if it is structured and supervised by health professionals?
- How do people come to know themselves when the activities in their life are focussed on deficits and inabilities?
- How might we as workers assist people to know themselves as members of the community?

- How can we invite the wider community to recognise the membership of people whose lives are troubled by the effects of mental illness?
- How can workers free themselves of traditional expectations to 'do for' others and instead move into the position of 'support with'?
- How can we assist people who, as a result of institutionalised practices, have been robbed of helpful ways of knowing themselves?

The team had some ideas as to answering these questions but valued continuing the questioning process as a means of avoiding the trap of replicating traditionally unhelpful practices of the past.

Women's group consultation

Further consultation then took place with a group of women who had been meeting regularly in a 'Worthy of Discussion Group'⁵. These conversations provided us with these women's thoughts on managing psychosis. They said that:

- *Help from others is best if it is firm but gentle and loving. It's best if it comes from someone you know.*
- *At times you need to repeat things frequently and firmly - the psychosis can get in the way of you hearing things.*
- *Allow us to talk - listen to us.*
- *Worst thing is someone who is impatient, angry, intolerant, unwilling to learn. It makes you sicker.*
- *It is useful to keep away from other people's negativity.*
- *Try not to be fearful of it (mental illness). Fear makes the experience even more negative.*
- *What helps is to be your own best friend - love yourself.*
- *These women also spoke of some positive messages you can give yourself.*

The women also gave us feedback on their experience of narrative conversations in the 'Worthy of Discussion Group'. They said:

- *The narrative questions help me build up a picture of what's going on for me. Over time that has helped me change my perspective.*
- *You can shrink from the task of changing. These narrative conversations challenge you to grow out of the sick feeling.*
- *Coming to the group is an assault on isolation, it was easier to stick to isolation before.*

Multiple family meetings

Our next series of meetings was with a group of families who had recently had their first encounter with mental illness.

From these meetings we gathered a great diversity of thoughts and ideas. We hope we have been able to do justice in this report to the richness of the conversations.

Encounters with mental illness

The families spoke about their first encounter with mental illness in the following ways:

- *You feel like you've been hit by a bus.*
- *You're in a state of shock at hearing the illness named.*
- *You're overwhelmed ... feel helpless and guilty.*
- *It alters the focus of your life.*
- *Despair.*
- *Mental illness made me think about the person all of the time.*
- *When you first encounter mental illness you feel very alone. You see other families at the hospital, etc., but you don't get to speak to them.*

Isolation

Isolation was a common theme and was described in the following ways:

- *It's like being in the dark.*
- *It separates you from the person.*

Challenges

Families described problems with communication and issues of responsibility as significant challenges.

Fear and anger were also talked about and were thought by the families to widen the gap between family members.

'Shoulds'

Family members talked about the 'shoulds'. They said they found themselves:

- *responding to other people's 'shoulds';*
- *being pushed for change that could be reached;*
- *being told that one is over-involved and should back off;*
- *and that these were all unhelpful situations.*

Unhelpful practices

Families identified practices they recognised as blocking them from being helpful members of their relative's team. Practices they named included:

- those that conveyed worker's sense of busyness and burden,
- attitudes of defensiveness, mistrust and secrecy;
- and practices that established an inconsistency of expectations. For example, that the family would be able to manage a demanding crisis (because they had been through it before) while at the same time needing a basic 'how to do it' manual on everyday living (because their family member might one day be in crisis).

Family strategies for bridging gaps

We asked families what ideas they had for dealing with the negative effects of mental illness. They said what was important to them was:

- *Recognising what it is - identifying things.*
- *Knowing that maintaining the status quo doesn't work.*
- *Negotiating reality.*
- *Slowing down the pace.*
- *Finding self-care activities and ways to feel positive about yourself.*

The families had some specific ideas about psychosis. It was felt that:

- *You need to take a stand against psychosis.*
- *It is good to talk openly about it when the person is experiencing the psychosis in ways that do not deny the person's experience. This means you know what is going on. You often get to hear about things and have an understanding that is not available to health professionals.*

The families' ideas for opening up communication included:

- *Reclaiming the past experiences of helpful communication.*
- *Being able to stay non-reactive and non-judgemental.*

In speaking about issues of responsibility, family members thought it useful to ask questions that invite a reflection on the impact that actions and thoughts have on others.

In speaking about their ideas on their relationship with mental health services, one group spoke about the importance of maps: 'You don't have to know everything about mental illness, but a map with guideposts would be helpful. Not a road to follow, because every road is different. Just some guideposts that can offer you different turns and routes.'

Inclusion

Families strongly favoured an approach that included them from the onset. They found that when they were all able to work together as a team, relationships became more natural and the pace more manageable. The idea of consultative teamwork was predicted to offer the evolution of more useful practical knowledge, and fewer occasions of crisis, fear and isolation for all concerned.

FINAL PROJECT MEETING

A final meeting was organised to give a report on the project to all six participating consultative groups. We also planned that this meeting would enable a cross-fertilisation of the ideas and experiences of those involved as consultants to the project. Our hopes were that this cross-fertilisation would honour and publicise the special knowledge all groups had acquired in dealing with mental illness, and that this might contribute to a bridging of the gaps. With this in mind we called together members of all the different consultation groups.

Before we could simply report back on the consultations however, we needed to ask the group of managers and workers who were unable to attend previous meetings because of busyness, to consider some of the questions that the other groups had discussed. These questions asked people to consider the impact of mental illness on their own lives and work. We also asked the managers to offer their ideas about dealing with the negative effects of mental illness.

In order to address some of the issues of power and privilege that might arise from such a meeting (in which service providers, managers, those accessing the services and family members of those accessing the services were present) those group participants who had already considered the questions became questioners and scribes as the workers and managers gave their answers and reflections.

The mental health workers' gave diverse responses to the question about the effects of mental illness on their lives and roles. Some workers had trouble thinking of the ways in which mental illness affected them. Some saw it totally

ruling their work role. They discussed the positive and negative effects of mental illness on their work practices.

In reflecting on the workers' conversation, the scribes wondered what it would be like for workers when the mental illness was ebbing if they only felt particularly purposeful at times of crisis. Another scribe wondered about the idea that mental illness required workers to see the funny side of things. She reflected on the effects on the possible implications for those on whom the jokes rested.

The scribes noted the practical and purposeful ideas which workers brought to their discussions about taking a stand against the negative effects of mental illness. They noted their desire to work co-operatively and fully. The scribes final comments related to the need for political and community responses, and for the development of more networking. They asked the question: 'Who will attend to these needs?'

At the conclusion of the meeting, there was enthusiasm for circulating further the ideas that had been discussed, for continuing the consultative process, and for publishing the project.

To end the meeting we invited everyone gathered to reflect on: 'In light of the experience of this collaborative consultation, what possibilities might now exist for all involved in mental health services?'

Reflections

The presentation of these ideas at the Inaugural Dulwich Centre Publications' Narrative therapy and Community Work Conference addressed an unmet hope that we and participants had held for this project – that others in the world of health and welfare and in the wider community would get to reflect on these views and knowledges. It enabled the experiences of the people who contributed their ideas about mental illness to the co-research project to stand with the women of the Power to Our Journeys Group with whom we co-presented.

Notes

1. The project was supported by the Director of this Service Alan Rosen with the encouragement and consultation of David Epston.
2. Raymond wanted to be known only by his first name.
3. This is a pseudonym.
4. This is a pseudonym.
5. O'Neill, M. & Stockell, G. 1991: 'Worthy of Discussion: Collaborative Group Therapy.' *Australia & New Zealand Journal of Family Therapy*, 12(4).