Doing it together

A collection of approaches, experiences and purposes of and in
Groups, Committees, Organisations, Networks and Movements

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Contents

Introduction

This book introduces consumers and others dealing with or working in the mental health system, to the presence and workings of all kinds of 'groups' in that system; we examine and offer examples of groups engaging in different types of processes, with different purposes and operating across the many levels on which our health systems 'reproduce' themselves: everyday life and survival, therapeutic experiences, committee work in organisations and programs, advisory and consultative work at different political levels, and in the 'private' and 'public' areas of health service delivery.

We will look at a variety of groups and identify their generic and their special features, offering them as *aspects, elements and factors to consider*, so that the inherent relational processes and experiences of working in groups can become as beneficial as possible and assist in reaching the purposes and outcomes they have been set up for and without being detrimental for the individuals who are part of them.

In this introduction, we offer a (very) brief summary of recent changes which have occurred in the mental health system in Australia, for the purpose of this publication, especially focussing on the *National Community Advisory Group*, but also, briefly, referring to overall developments in the social/societal responses to mental ill-health. A second section will introduce general aspects of groups (and to a lesser degree, organisations) as *relational systems and processes*, including their 'management', group membership and leadership as complementary relational roles, tasks and other purposes of groups and considerations about the 'individual' in the group. A final section will introduce the contributions to the book, offering

examples of the workings and purposes of groups, operating at the various interconnected levels, across which the operations of mental ill-health services are deployed.

1. The Australian mental health 'system' and developments in the last decades

The ways in which mental health and mental illth have been dealt with in Australia and other industrialised nations have dramatically changed during the last centuries and even more dramatically during the last four to five decades. Whilst we cannot offer the full story here, some highlights of the changes in dealing with and maintaining '*mental health*' and 'preventing', 'curing' or 'taking care' of '*mental illth*' will be mentioned; we will briefly illustrate how the main *philosophical* approach – and to a lesser degree, policy and practice - has moved from institutionalised and medicalised 'care' via '*deinstitutionalisation*' to consumer-integrated legislative/policy/delivery practices and inclusive praxis.

We can't elaborate much on the long-term changes in the ways in which people with mental 'illth' conditions have been treated or more generally dealt with in western societies and communities; written in the 1960s, first published in the 1970s and republished regularly since, Thomas Szasz' '*Manufacture of Madness*' (last edition at Syracuse University Press, Syracuse, 1997) remains a critical guide through the evolution of the 'story' of mental health (as is Andrew Scull's more recent *Madness in Civilisation: A Cultural History of Insanity* (2014), Princeton University Press). The second half of the 19th and the first half of the 20th centuries are usually credited with the major advances in the 'scientific' understanding of the genesis of the *psychological* aspects of mental illth and psychotherapeutic responses thereto (from Freud's and Jung's psychoanalytic approaches to the behaviouristic and cognitive models slowly moving to such approaches which were less directive and more holistic, slowly including social-relational parameters in the understanding of the aetiology of mental illth). However, another type of scientific breakthrough was John Cade's invention of *lithium* in the 1960s and its growing application in the area of medical intervention into mental illth, which indirectly and partly 'allowed' the emergence of the de-institutionalisation processes across the world.

The trend towards developing therapeutic communities inside and outside the psychiatric hospitals (Maxwell Jones, Laing, Cooper and many others; see Manning (1989) *The therapeutic community movement: charisma and routinization*) emerged during the 1950s and was essentially a participative, group-based approach to mental illness. It was, in part, thwarted by deinstitutionalisation, as the necessary

intermediate and community-based alternatives did not eventuate because of neglect and lack of funding (see Taylor Duren, 2015 https://www.youtube.com/watch?v=hLV9r9kkVqs). As well, community-based alternatives to *both* fully institutional 'enclosed' 'care' and fully de-institutionalised care have been existing for centuries, the example of Geel in Belgium being the one which has been researched extensively (see: *A Model of "Community Recovery"* http://faculty.samford.edu/~jlgoldst/)

The 1993 Burdekin Report (*National Inquiry into the Human Rights of People with Mental Illness*) was a milestone in the Australian road towards the *First National Mental Health Plan* (1993-1998), where the Federal Government entered the debate about the provision of mental health services. For the first time, this brought consumer and carer participation in decision making, as well as the 'discourses' around case management, the introduction of the idea of 'serious' mental illness with a focus squarely on *organic* illness, somewhat at the expense of identifying past trauma, psychotherapy and any concentration on 'therapies' other than psychopharmacology and attendant community participation, mainly for people experiencing psychosis.

National Community Advisory Group

During the late-1980s, much unrest reigned across the national Mental Health 'system'; doctors working in the public sector and 'carers' of people with 'mental illness' were tired of the neglect of public mental health services right around Australia. They put pressure on the Keating Labor Government to act.

Change started at a federal level; Brian Howe, Minister for Community Services and Health, had a passionate commitment to mental health. In 1989, he commissioned the then National Human Rights Commissioner, Brian Burdekin, to explore the state of public mental health policy and practice in Australia. *The report of the National Inquiry, concerning the human rights of people with mental illness*, became known as the 'Burdekin Report'. It was scathing of public mental health services across Australia.

As part of this revamping process, the community - largely carers at that stage - were demanding to be heard, the argument being that skills and expertise present in the community could advance a change agenda past bureaucratic malaise and professional resistance. There were several initiatives, introduced in the *First National Mental Health Plan*, to include consumers in mental health decision making, the most important being the *National Community Advisory Group* (NCAG).

Creating a group with uneven numbers of consumers and carers was a mistake; on the one hand, imagine years and years of neglect and the start of a radicalised consumer movement; imagine a 'survivor' agenda for widespread social change; imagine consumers demanding a whole new world encompassing changes in community attitudes, in carer patronising, anti-Big Pharma (pharmaceutical companies) and wanting to tear down the existing symbols of their oppression. On the other, imagine a group of frustrated carers who were driving a change agenda from a conservative point of view; they were middle-class, articulate and passionate; they wanted more and better, not less and different.

The first years of NCAG were very volatile; decisions didn't get made because the many years of neglect had built up much anger. Carers didn't understand the reason for consumer anger, at the process and at them; they didn't understand that without good process, they couldn't bestow 'good decisions' 'onto' consumers. At a meeting in Darwin, matters came to a head and the secretariat realised that the differences between the two groups would remain irreconcilable unless changes were made.

In those early days, a decision was made that the Chair should be someone famous, able to bring public recognition and credibility to the NCAG. The first Chair was Trish Goddard; one of the great achievements of the NCAG was the transformation it generated in Trish – she shifted from actress to consumer. At first, no one knew about her personal journey with mental illness; she spoke as a carer; everything changed when she chose to be direct, a simple but important decision, symbolically as well as practically and especially for consumers.

Consumers, however, were still seen as the *stories* in the conversations, rather than as *commentators* on those stories. A decision was made to appoint two extra consumers, creating parity with carers on the NCAG, which didn't completely solve the problem, given the greater power to direct and control the latter could muster; as well, all carers saw, presented and therefore represented **psychosis as** (all that was relevant in matters of) **'mental illness'**. Whilst the consumer voice was not as narrow, the balance of power often still relegated different consumer priorities to 'other business', as everyone raced out of the door to catch a plane.

Given the structure of the meetings, it was impossible to think about the deep, abiding issues at the centre of all things in mental health; instead, the NCAG remained reactive, bureaucratic and clumsy, with oppressive and annoying hidden agendas. We knew that many attempts to fight for things important to us would fail. Returning home from the meetings, we were then accused of being elitist by other consumers and organisations. Debriefing? Our choice was a 'posh' carer from another State or nothing! Much was oppressively 'confidential'.

The NCAG wasn't a disaster, however, and the tensions between consumers and carers lessened when two more consumers were invited to join to balance the numbers between consumers and carers, but they never completely disappeared. Thankfully, (most of the time) the tensions were not swept under the carpet, which is what sometimes happens today. A thrown book of proceedings can easily be replaced, but accepting a lie, for the sake of peace, is much more damaging.

The carers were, without exception, focussed on action and change in services and *not*, as we were, desperate for changes in '*the world*'. They hated '*just talking*', often making moral judgements of the kind: '*there are carers out there whose loved ones need to be in hospital, while we are just sitting here talking about abstract ideas.*' On the other hand, many consumers in the group were frustrated with these calls for action, which, in our experience, usually meant more of the same: more medicalisation, more pharmaceutical companies, more un-thought-through community awareness campaigns, more of the same sort of research and more diagnoses. As a testimony to this dichotomy

within the NCAG, its first public report was – strangely - titled '*Let's Talk About Action*'.

An Aboriginal member of the NCAG, in particular, was uncomfortable as the tokenism in her appointment felt obvious. Those who attempt to construct groups like the NCAG to *look* inclusive and 'representative' were able to 'tick off,' in one person all of Aboriginal, woman, lesbian and regional/remote. If only information had been properly 'passed down,' to the groups she 'represented', much could have been learned!

Formal meetings are perhaps the least creative form of group engagement; people hide behind rules and mores, behind which bureaucrats and some others in the group feel safe, but which stifle new and exciting ideas, real inquiry, healthy troublemaking, important relationships and creative thinking.

So, not only potential clashes of perspective exist between consumers and carers (now often camouflaged by the language of '*lived experience*') and problems caused by purpose and function of groups like the NCAG; there is also the subjugation of minority positions, which is still different from the tokenistic inclusion of minority groups. Some such minority views might include anti-psychiatry positions, fundamental concerns about the effects of childhood trauma, a yearning to understand and incorporate social imperatives or fighting for the rights of unpopular causes.

So we did learn about the limitations of structured groups like NCAG – 'committees' - to bring real change. On the other hand, as a catalyst for the recognition of consumer leadership that was to follow during the nineties and for the establishment of Consumer Advisory groups at

State and local levels, the NCAG deserves a place in history (see Merinda Epstein's contribution in this book).

This brief personal account of participating in one type of 'group' in the Mental Health context powerfully illustrates the range of relational and process issues at work in groups. We will explore these in the following section and, of course, in the case examples throughout the book.

2. Groups, organisations and other 'relational systems and processes'

If it is true that our species is essentially '*cooperative*' (Bowles & Gintis, 2011), altruistic and empathetic (De Waal, 2009) and if Novak (2011) is correct in saying that we are (meant to be) 'super-cooperators', why then are so many of our fiction and non-fiction stories all about competition, the celebration of individualism, even suggesting that life is an eternal battle of all against all…? And why do the rules and visions supporting and justifying our economic, political and social-relational regimes (or regimes of 'truth' as Foucault would have it) continue to emphasise the imperative of competition, of the necessity to maintain power differentials and inequality and of the axiom of the 'survival of the fittest'? I still vividly remember the giant billboard along the final section of a suburban freeway in Melbourne, brutally screaming at the thousands of stranded morning rush-hour car commuters: '*Don't just sit there… call your competitor's clients…!*

One should also wonder why *individualism/ cultural and pathological narcissism,* (as recently splendidly explored by Anne Manne in her *The Life of I* (2014) and by Paul Verhaeghe in his *What about me?* (2014) Scribe, Melbourne), has

so encroached on and 'infested' our personal and social ways of being and relating that we consider them as the 'normal' and 'natural' modalities of human existence. Indeed, the systems – institutional and organisational – we 'inhabit,' have so deeply incorporated the '*divide and conquer*' intentions behind this individualism, that they appear as the *normal structural embodiments of our collective lives* and those who protest against such unnatural impositions, or otherwise suffer from them are punished, marginalised and otherwise excluded. More to the point, they are often 'diagnosed' as in need of 'adjusting' social and personal interventions, to 'keep' them in emotional, relational and many other ways (at least) within the periphery of 'normal' community/society (if they, indeed, 'deserve' it…).

Obviously, this is not the place to unravel the seeming contradictions inherent in our perceptions of humans as – either – individuals *first* – or – social 'animals' *first*, nor is there space to examine understandings of humans as *both* individuals and social beings and of how different times and cultures have dealt with the inherent tensions and complementarities. What can be said, though, is that there is now a strongly emerging consensus on the essential nature of '*relationality*' and '*connectivity*,' inherent in the human species – indeed, there is recognition that the 'hominids' families of species would not have stood a chance of surviving, the 2 million years since their emergence and evolution, if they had not been fundamentally *cooperative*.

So even if their exploration is not part of this collection of examples of collective endeavours or 'working with and in groups', the book rests on the converging evidence and broadening understandings, derived from several scientific

endeavours, that we are primarily relational beings. From the social sciences to relativity and quantum-mechanics theories and from ecological and Indigenous understandings of what it means to be human, to the growing neuro-scientific discoveries of humans' capabilities to 'mirror' social, altruistic, reciprocal behaviour, they all converge on the need to re-think 'us' as essentially social beings first. They also converge on the complementary realisation that – given the damages done by narcissism and imposed competition - we'll have a great job on our hands, to regain our capability of 'relational being' (Gergen, 2009), if we are to regain our chances of survival, with degrees of personal and collective wellbeing, in an already damaged ecology.

Underlying questions this collection will *not* attempt to tackle directly but which are part of the subtext of most contributions include:

- Why is it important to live with, do with, be with others?

- Why we are sometimes forced out of our relational ways of being by assumedly 'social', economic and institutional expectations?

- How and why are these 'structured' expectations incongruous with our natural cooperative, relational ways of species-being?

- How can we re-engage consciously in relational and reciprocity-conscious decision making – in groups and collectives with therapeutic, practical, political, administrative, etc. purposes - which would 'allow' our cooperative 'instincts' to flourish and be sustained?

- How can we re-conceive of relational *ways of interacting* rather than seeing and experiencing them as expressions of a (presumed social) 'contract'?

- How can we look at social groups, organisations and systems as on-going processes of resilience-creation and maintenance, indeed as the opposite of their 'crystallisation' into bureaucratic command systems, demanding compliance and only (sometimes) reacting to formalised complaints?

This volume includes contributions about different sorts of groups, collectives with different purposes and philosophies and operating at different levels – local, state-wide, national and even global - and within different 'systems' and social contexts – private, public and mixed. Some chapters will examine 'group work' as a *process of purposely relating*, purposes possibly attached to the individuals being part of the group, or to the group itself as a relational/productive system and process, or to a 'task' or 'role' external to the group itself but to which the group's work is instrumental. Other chapters focus more on structured collectives or organisations, more or less formalised relational systems of on-going exchange and productivity, operating from the local and short term to the national or global and long term. Questions will be raised about how to keep groups or organisations 'going' and principles and suggestions will be offered for increasing the 'resilience' or capacity of groups or organisations to deal with change along with descriptions of process, composition and intent.

Receiving and working through the contributions, what has become ever clearer to us, is how *divers*e and often *paradoxical* the mental and experiential associations people have with

'groups' are; this becomes comprehensible only when we connect the 'proximate' and personal experience-saturated image of a 'group,' we are or have been part of, with the diverse 'uses' and 'expectations' that are associated with them from the inside and/or from the outside. The groups, we offer the reader for examination, thus range across the entire continuum, from the 'personal' to the structural and institutional, from the 'private,' via the non-governmental, to the 'public'. The book, hopefully, will assist consumers in better understanding the existence, workings and generic value of 'groups,' in contexts personally relevant for themselves, as well as for promoting appropriate service delivery and representation of their strengths and needs. We thus hope that it contributes to the specific purposes, modalities, processes, expectations, relationalities and compositions of groups, as well as their meaning for – on the one hand – the individuals which are part of them and – on the other – for the social configurations/contexts in which they operate (from micro- to macro-contexts, e.g. communities, (local) service delivery agencies, political/economic decision-making structures, from the local to the national and sometimes beyond...).

A little attempt at describing what groups and other relational systems are and how they function

Groups may be defined in many ways and it is very problematic - and indeed contestable – to try and do so. Broadly speaking, a group is gathering, of varying numbers of people, who have come together to engage in a relational process, for some more or less defined and commonly understood purpose; so, one could say that a group consists of *two or more individuals who are connected to one another by social relationships*.

Some characteristics which are common to lots of groups include:

- There is a set of people who engage in (frequent) interactions;

- The members – to varying degrees – identify with one another;

- They are understood and recognised by others to be a group;

- They share – to varying degrees – beliefs, values and norms about areas of common interest;

- To varying degrees, they will define themselves as a group;

- They gather to work on joint tasks and for – more or less – agreed purposes.

Working in and through groups can be about *individuals helping each other*, about *helping groups and/or individuals*; it can be about *influencing* and *addressing* issues of a personal or group nature and/or of organisational, community and even societal portent. Meeting in groups can thus be seen as creating occasions and opportunities to share thoughts, ideas, issues and activities and to engage in conversations, which address issues of importance for the members, both within the realm of the group itself, or for the context within which the members live and by which they are.

Groups can therefore be:

- sites of socialisation and education – enabling people to develop a sense of identity and belonging, to deepen knowledge, skills and values and attitudes;

- places where relationships can form and grow and where people can find help and support;

- settings where wisdom can flourish as 'the many are smarter than the few';

- settings where participants can get a sense of their common strength, both in spite of and because of their differences;

- effective organisational sites from which good and desired change 'in the world' may emanate.

Each of these possibly benevolent outcomes, of course, (may) also have its downside... The education and learning groups offer might constrain and be oppressive for some members; groups can create and worsen interpersonal tensions; groups may exclude certain people and inter- and intra-group conflict may occur; groups can influence members in ways that warp their judgements and that lead to damaging decision making ('groupthink'); groups may not have the appropriate composition and necessary set of skills to successfully reach their purpose. Because of the nature of their operating context (i.e. the broader environment in which groups operate, e.g. institutional and political/economic contexts), groups may experience a variety of pressures and influences which need to meaningfully dealt with lest the group (or, for that matter, the organisation) may experience pressure while not being able to determine the origin.

Dimensions of group processes most often dealt with in the literature include:

- Group interaction and process

- Group interdependence and cohesion

- Group structure, including leadership and roles

- Group goals and purpose (linked with task)

The most influential model of the developmental process in groups has been that of Bruce W. Tuckman (1965; 'Developmental sequence in small groups', *Psychological Bulletin*, 63, 384-399). While the number of stages and their names may vary, many have adopted a version of Tuckman's model – **forming, storming, norming and performing,** to which he later added **adjourning** for groups anticipating their closure.

More practically and lightly scanning the territory of mental health and consumer groups, groups can be about *decision making* (e.g. committees, commissions, steering groups, working parties, etc.); they can be about *seeking and analysing information* (e.g. discussion or focus groups, research or evaluation groups); *political groups* can be about campaigns or advocacy; and then there are groups which don't want to enter any sort of decision-making but are about *collaboration and mutual understanding, casual groups associated with service delivery, educational and friendship groups*." Finally, there are groups which adopt *therapeutic qualities and intentions,* either in hospital or in dedicated

forming

storming

norming

performing
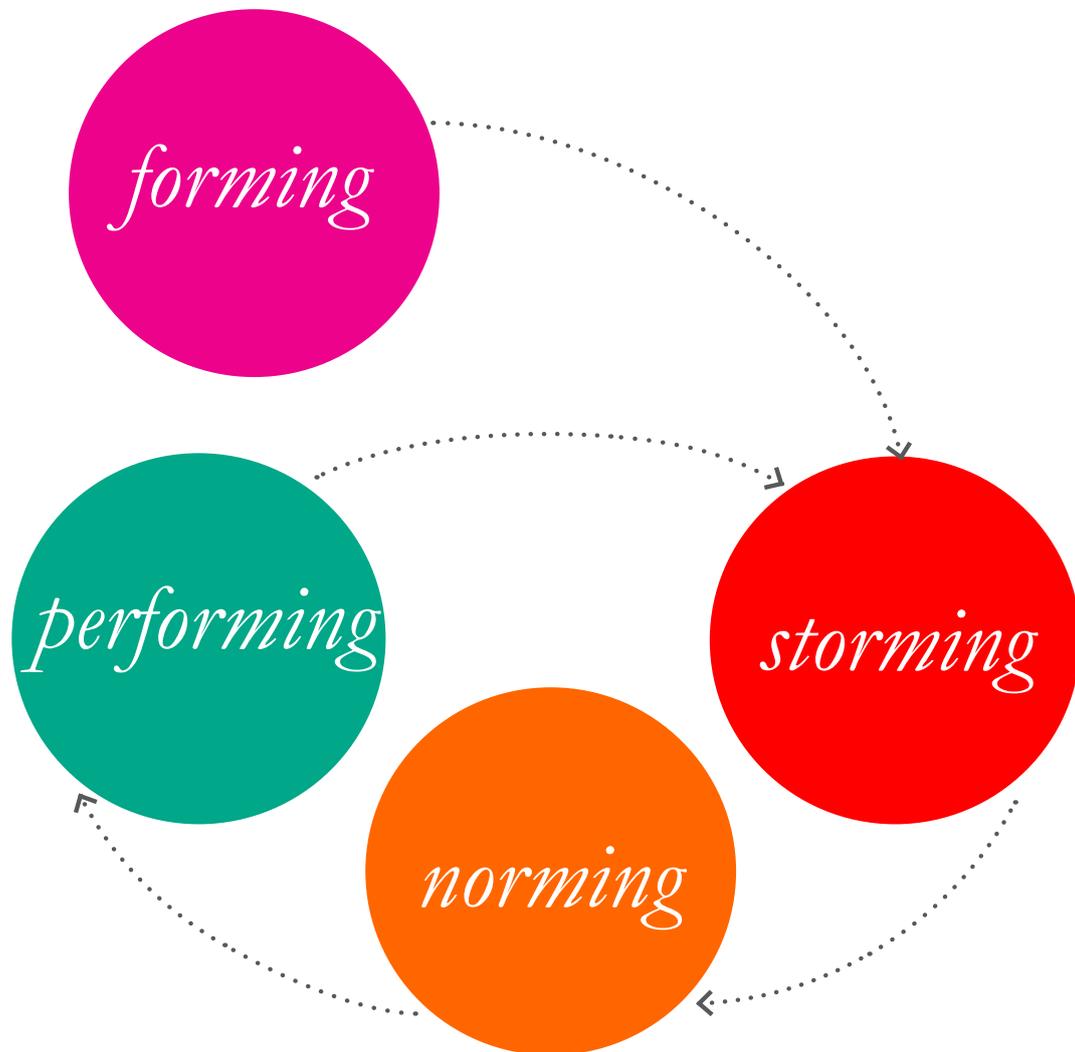
community-based organisations; they are more or less purposefully organised to address the personal situation of consumers, as they traverse the continuum from ill-health to health and full integration in the communities, of which they are part or desire to be part of.

Organisations

Individuals working and otherwise congregating together *construct and generate organisational structures, processes and practices*, which, in turn, *shape social relations and create institutions that ultimately influence people themselves.* Organisations are often defined – with sometimes very different emphases - *as social units of people that are structured and managed to meet a need or to pursue collective goals.*

We cannot possible elaborate in any detail on 'organisations' – and neither can we deal with networks and movements – but we do believe that the *relational* undertow of all social processes and structures is worth examining;

thankfully, much of the theoretical and practical developments, over the last two decades, have slowly but consistently moved in that direction.

3. Introduction to the contributions

The following series of contributions illustrating the 'workings' of groups and organisations of many various types is presented in a '*landscape*' which offers a conceptual context to reflect more accurately on the 'story' being offered from 'inside' the group or organisation itself. There are three 'sections' within this landscape, travelling from the 'macro' to the micro/(inter)personal 'level' and offering experiences and insights from working through and with groups in the relevant organisational and institutional contexts and inviting the reader to reflect on 'the use of groups' in those 'spaces' and with the respective groups of collaborators, peers, consumers, etc.

- **Section One:** working the interstices/interface between consumers, consumer organisations and networks and society-at-large, its institutions and the collective interests of consumers.

Merinda Epstein leads in with an article based on her own experiences (as illustrated earlier in this introduction) about setting up Consumer Advisory Groups (CAGs) with a special focus on Victoria. In a second contribution, she reflects on her experiences of 'being consulted' and shares her wisdom about process and urges those who engage in consulting work – both consumers, their groups and those 'doing' the 'consulting' – to include appropriate ways of research and evaluation in their consulting efforts.

- **Section Two:** working with and in groups and committees, by and with consumers regionally and locally, operating to transform agencies and service delivery systems and processes and create learning processes between consumers and professionals.

Allan Pinches leads in with a discussion about – what he calls – 'time-limited' groups and how they can be used by consumers to their advantage health-wise as well as in support of their living conditions. This is followed by two further contributions by Merinda Epstein; the first details her experiences as part of the 'Deakin Workshops', which could be seen as 'pre-figuring' the now commonly referred to approach of 'service co-production'. The second article – again deeply experience-based – reflects on 'deep-dialogue' groups as trialled by VMIAC during the nineties in Melbourne.

- **Section Three**: working with and amongst consumers in healing, mutually supporting groups – both peer-led' and professionally 'moderated'- and in places and organisational contexts supporting people with 'different abilities'.

A first 'sub-section' is introduced by Liz Carr, who makes a case for 'peer-led' or 'peer-run' consumer groups, identifying the strengths and capacities of consumers to assist others and themselves in surviving and flourishing in a social context which – in so many ways – does not understand what is at stake. This is followed by two 'lived-experience' accounts - Grow and the Maine Connection – about two local groups and organisations which practically and philosophically illustrate the 'peer-led' approach.

The second 'sub-section' – opened by Ann Tullgren's '*There are Therapy Groups and then there are… groups*' – offers four examples of 'therapist-' or 'professionally-led' groups,   two in Fiona Mc Dermott's article, the Prahran Mission's *Hearing Voices* Groups and Andrew Mc Ness and his colleagues' *Compassionate Friends* initiative for bereaved parents, siblings and grandparents. Ann's piece meaningfully 'warns' consumers to be diligent in their appreciation of therapeutic groups and – more generally – all therapeutic interventions, whilst the three following articles offer illustrations of approaches to the use of groups either generally or for more specific groups of consumers.

A final sub-section includes one article by Jacques Boulet of the Melbourne-based Borderlands Cooperative, a community-based organisation and 'place' which offers inclusion opportunities for all comers, valuing and validating the strengths and capabilities anyone brings, including people with disabilities – or, as the Borderlands philosophy prefers to express it – people with all abilities.

{*Setting up Victorian Consumer Advisory Groups (CAGs) – an overview*}

Merinda Epstein

Setting up Victorian Consumer Advisory Groups (CAGs) – an overview

Meetings and Power: "Knowledge is not knowledge. Knowledge is always relative to the power of the knower…"[2]

Local CAGs [1]

To a large extent, local CAGs in Victoria resulted from decisions made, by the Victorian and Federal Mental Health Branches, in the first half of the 1990s, when respectively the *Understanding and Involvement* (U&I) and the *Lemon Tree Learning* Projects were funded. CAGs are therefore deeply embedded in the annals of the Victorian Mental Illness Awareness Council (VMIAC), which sponsored and encouraged these projects. The idea of '*consumer consultants*'[3] emanated from the research in the *U&I* projects,[4] as we learned that, left to their own devices, staff would never get around to doing what was needed to build '*everyday consumer perspective evaluation*' into the practice of acute units. From the *Lemon Tree Learning* project we learned that, *consumer education of clinicians* had to be built into everyday deep culture change in situ.

Over time much has changed and evolved.

Consumer consultants gradually made themselves indispensable, not just in acute units but in all areas of clinical services and then in community services as well. Peer support workers joined the workforce and a few consumers became managers of the consumer workforce in their service. A small number of consumer-academics were employed in universities and consumer-clinical educators in services. Consumer staff demanded supervision for these very demanding roles and consumers were employed as supervisors.[5]

As the scene became more sophisticated and, perhaps, more complicated, the idea of CAGs re-emerged as a good way to hear from a variety of consumer groups, consumer interests, consumer views, consumer expertise and different levels of engagement and experience. At a local level, CAGs are generally part of an organisation which provides services, e.g. clinical organisations or community organisations, and they may or may not be supported by consumer consultants.[6] Regularly bringing together a group of consumers, from a service/organisation, seemed like a good way to gauge the temperature of the organisation on a regular basis and challenge it from a critical consumer perspective.[7]

This has not been without its challenges and they obviously differ from site to site and from organisation to organisation. There are many incarnations of the CAG concept, but there are indicative common themes.

Setting up CAGs

People, who have been active in Victorian local/organisational CAGs, report that the way it is set up is fundamental to its success; a poorly conceived CAG can lead to impotency, frustration and sometimes an early demise. In order for CAGs to succeed they must be a project of consumers and a service/organisation, and consumer consultants/peer workers should be the central plank in the formation process. This is sometimes called '*consumer driven and staff collaborative*'[8] or, a newer term, '*co-produced*'.

In order to do this, consumer peer workers need to do their homework. It is unlikely that others,

in the organisation, will have any more than a cursory idea of what a CAG may or may not be and how it works when operating optimally. In order for this to take place, services/organisations must value the mechanism sufficiently to allow peer workers time, space and capacity to complete the preliminary work, including visiting and engaging with consumers in already established CAGs.[9]

> "*We can do everything, but if we don't have the support of organisations then we won't get anywhere.*" (Consumer at Training Day, VMIAC November 2014)

As there are many issues to think through carefully, the development of a CAG has to proceed at its own pace and that pace which will differ for a myriad of reasons. The more that can be done before the first meeting the better, but it is optimistic to think that there won't be a need to adapt and change as CAG members learn on the job.

Early Configuring:

Selecting members: Who?

Geographical coverage and representation may be important for some CAGs, so groups of consumers from a geographic area are chosen locally to be part of a more central CAG.

CAGs may be more local and a truly democratic process may elect all CAG members, voted on by a general election process.

CAG members may be chosen by the '*divining rod principle*' (see chapter on Deep Dialogue), where those with most energy and greatest predictability of longevity might be chosen, passion for the job being the primary criterion.

Members may be chosen with an eye to *diversity*, ethnicity, gender, age, class, age, sexual

preference all taken into account to try and insure that those with least 'natural' authority are in the mix.

Members might be chosen with other minority characteristics being considered; e.g. a cross section of educational backgrounds, diagnostic label backgrounds, childhood trauma backgrounds and diverse political views.

They may be selected from a mixture of all of the above.

Selecting members: Process

The choices that exist for all nominally 'representative'[10] bodies apply to CAGs; members can be chosen centrally by the CAG, nominated by groups represented by the CAG or self-nominated.

This can be done by election or selection of those who are perceived to have the approach and the skills that will enable the CAG to function most usefully.

The process may include the presentation of a CV, setting out a person's experience, education and addressing the most important requirements for the position as a CAG member. This could be daunting to some and assistance should be available if required.

The process might include a formal or an informal interview.

Induction:

> "**Me-tings** (noun) *Meetings where nobody is listening to each other and everyone is simply practicing what they want to say next*"[11]

People need training in order to understand their role on a CAG; training must include pragmatic things, such as the way CAGs and meetings work[12] and how decisions are made; some

important information about commitment, expectations, payment, confidentiality and how bureaucracy works. This part of the induction program will develop with experience and time as the CAG matures.

People may need to understand the consumer movement and its history, the *mad pride* movement, important consumer debates, such as anti-psychiatry and the role of pharmaceutical companies in funding research, consumer language and discourse, understanding the critical consumer perspective and the ideas behind co-production. This is important to boost the future capacity of the CAG, and to avoid it being swallowed up by the dominant discourse of the organisation. However, people should not be bombarded and intimidated; the material should be presented in an accessible but not patronising way.

As the consumer movement has a long history of intra-consumer turmoil, it's also useful to offer a context for this and discuss ways in which dislocation and demise can be thought about and avoided.

Principles of recovery of a group, are as important as principles of personal recovery.

No group will continue to function well, if everyone is simply out to force their own agenda through no matter what. Training needs to include defining what CAG means, meeting rules, problem solving and negotiation, devolving responsibility and sharing the load, assertiveness, expectations and how to use supervision if provided.

Some input will be from inspirational consumer leaders, who will know what is important for new CAG members to know and why and how that is so.

Starter Kit/information packs for CAG members

Whether developed before the recruitment, of the first sitting members of the CAG or developed by them, the collection and production of a '*Starter Kit*' for new members is worthwhile and appreciated. It may have fundamental information about the service and the organisation; the structure of the community services sector in Victoria and the clinical sector; the history of CAGs; information about role and function of CAGs and its members, including information about personal safety, relevant policies (but don't overdo it) and a template for a meeting; … and of course, some (pleasant) surprises as well. It may include information about advertising for new members; information about how to set up a safe CAG and run induction safely and productively; and all the important stuff about the organisation and the system(s) within which it works and must survive; finally, information about the history of the consumer movement and essential consumer/survivor/user sites on the internet[13] and the rights movements in Australia and globally.

The orientation or information pack should be designed to avoid being text-heavy, with no barriers around literacy, but with top-up information available for those who want it.

Structure, function and context

> "Maintaining regular groups [is imperative] but they must have purpose, capacity building and leadership, 'launching pad programs' and organised development."[14]

Structure

The way the CAG is structured and the way it is required to function, are two of the determinants

of success. Research[15] has shown that initiatives that are not built into the structure and fabric of an organisation or service will have little success in changing service culture or achieving practice and structural change. CAGs that are not linked directly to formal decision making structures will end up being irrelevant; it must have teeth and it must have authority to hold management to account.

CAGs must be set up in such a way that only a small amount of time and energy is spent reacting to '*others' agenda*'; without this firmly in place and without the structure in place to limit exploitation by others, within the organisation/ service, the group will flounder under the weight of demands to comment on mountains of others' documents. The CAG must be focussed and its members and the organisation or service it advises must be aware of this focus, determined by a consumer-driven, staff-collaborative process. The structure of the group needs to be such that, there are different people with different areas of specialist expertise and these specialists can take responsibility, both proactively and reactively, for their specialities. This might, but will not necessarily, equate to areas of disadvantage such as minority groups in the community. These groups might be trained consumer educators, people experienced with community treatment orders as patients, qualitative researchers or people with a strong interest in childhood trauma.

It is suggested by some that in designing a CAG, a maximum time of tenure be established and this should be around about two years. Consumers are divided, however; there is an argument that enthusiasm should be rewarded and that natural attrition will keep the CAG relevant, with an adequate turnover of members. Disruption to membership should be minimised, with terms of

engagement being negotiated to achieve this. The structure should clearly articulate communication channels between the organisation and the CAG, both needing to be accountable to one another.

Building CAGs In[16]

"The mental illness industry is the only industry where the customer is always wrong" (Mary O'Hagan Mental Health Services Conference Consumer Keynote, 1994)

Organisations need to prove to consumers that providing for a CAG is now routine and that they couldn't imagine the organisation without them. This 'absolutely necessary' quality is a sign, that the need to listen with full attention to the needs (not perceptions) of their customers has, at last, sunk in.

CAGs are one of a variety of mechanisms in place, in the community and public clinical sectors in Victoria, to ensure that services and organisations are responsive, to the needs and wishes of the people they are, primarily, there to serve. They are what Wadsworth[17] calls the *Critical Reference Group* (CRG), differentiating consumers from other stake holders and institutionally positioning the CAG as more important than most other committees.

The CAG is essential, but only as a part of an interlocking set of mechanisms that, together, make up a consumer portfolio, including peer workers; consultations with consumers; feedback mechanisms; funded consumer-led research; co-produced research and evaluation; consumer educators; consumer clinical supervisors; consumers on the Board and on other influential and governance bodies and consumers sitting on external bodies, which have an influence on the

role and functioning of the organisation. CAGs need to be deeply imbedded into the processes of the organisation and consumer participation must penetrate right through every aspect.

Function

If a CAG has no formally-stated function it won't work and its actions, recommendations and presence won't be taken seriously; it will be token consumer leadership and, most importantly, it will be a waste of precious time for consumers. The purpose must be clear, recorded and known by the organisation and all staff, as well as consumers on the CAG. Everyone must be clear that it is neither a therapy group, nor an occupational therapy group; unless there is meaningful participation, in relation to a formally stated function, it may end up simply lacking meaning. It needs to be creative, contemplative, courageous and proactive and move deliberately towards becoming indispensable.

The CAG is not 'just another committee', though it will take an effort to convince some staff of this. To some extent, consumers have to prove their worth and collectively, the group also needs to prove its worth. This creates challenges, as judgement of worth is often in the eye of the beholder and if worth is demonstrated by counting the number of organisational documents a CAG has churned through and granted its imprimatur to, discussions about *appropriate function* are necessary. Sometimes, appropriate perusal of documents is necessary and everyone needs to know, not only the context of these documents but also their status and who/which groups will comment further. There is no point for CAGs to spend a lot of time commenting on documents if someone '*up the chain*' will just reverse all suggestions. This is disrespectful

process; ideally the CAG should be very near the top of the chain in these matters; after all, they represent the people the service (is meant to) serve.

The CAG has multiple functions and one of them is internal debate; ideas are important and like in any group, people won't agree on everything. Some of its work is to *prefigure* or act out good practice in advance, new ways to co-facilitate, co-produce, enable power to be taken up, share the load, use respectful language, listen in new ways and do committees differently. This means that CAGs could become models for consumer-inclusive practice across an entire organisation. Real shared decision making is something hierarchical organisations find difficult and CAGs need to constantly be aware of *building* capacity rather than allow it to 'leak,' which happens when people's knowledge and skills are ignored or underutilised.

Once a decision has been made that a CAG is not primarily a *reactive* body, it has the responsibility to work out what it really wants to do, within the service/organisational context. This probably requires a facilitated workshop! It is hard to predict what the differences between people may be, but generally there are some who primarily want to 'do' and others who primarily want to 'think collegiately'. Both are important and weighting them so that a productive balance can be achieved is important. Some of the thinking about *proactive* responsibility will already start with the selection criteria for the group and how these criteria were chosen. If minority groups, for example, were a selection priority, this will determine some of the work that might be prioritised. It's imperative that decisions, about what is to be explored and pursued, be owned by the CAG.

In this context, many people talk about *community development* without really understanding what it means; it firstly *honours community*, honours being communal, honours *relationships*. It slows things down. It does not bend to bureaucracy. It fights for powerless people. It doesn't like committees for the sake of them. It is local. It is fair and it exposes *power-over* tactics and those who would be bullies. Community development is one of the cornerstones of the consumer movement; it doesn't worship meritocracy nor - necessarily - the manager. It is careful with its language. It is brave. Community development can be harnessed for CAGs to build the capacity of its members, of consumer groups, of people. Abiding by the principles of community development is important as it builds the 'group-ness' of the CAG preventing it from becoming a group of isolated individuals fighting for individual causes at everyone's cost.

Context:

> "**Morning Teas** (*noun*) *Beware any meeting where more money is spent on morning tea than on commuting reimbursement for consumers*". (MadQuarry Dictionary[18])

CAGs are formed within the context of an organisation, an area or a region and they are there '**for**' something or somebody; this will influence the way they work, without overriding the fact that consumers must feel and demonstrate ownership over **'their'** CAG.

Other contexts for the work of CAG members can also be important; it is very different if a member is asked to sit on a research committee or give comment for consideration of the CEO of the organisation or organise consumers to give talks about their lived experience of receiving services from the organisation concerned. Each of these contexts demands different approaches and - maybe – the input of different members of the CAG. As CAGs become normalised and more consumers become involved, they will develop areas of interest and expertise; they will specialise.

As CAG members get better at realising that no-one is always right for everything, no matter how much they claim to be '*representing*' a constituency, the organisation or service will gradually learn the real interests of different members, as will the chair. Members will learn when to take on an opportunity and when to handball it to others, which also takes a degree of humility. It means also that members will be less likely to be overburdened and the organisation will benefit the person with the most appropriate knowledge and skills as well as a range of views. As CAGs become essential, so too will their advice be sought and differentiation will be made between research committees, education committees, advocacy advice committees, media sub-committees, communication policy group, the Board, consumer activity committees, finance sub-group of the Board, Culturally and Linguistically Diverse sub-group, access committee, service development committees, etc. All of these have a context too: a particular skill set, culture, history and, importantly, sitting members who may or may not be amenable to consumer participation.

Given the reality of small CAGs in what are often huge organisations, prioritising is essential and needs to be managed. Members may privately (usually because of their lived experience of pain) have differing priorities; without denying the power of pain to determine all of our lives, not everything can realistically be covered and ordering possibilities in a manageable way is essential. Looking after the labour capacity of CAG members and utilising other consumers is vital to leave room for creative pro-activity.

Safety, Support, Training & Victorian website

So many consumers experience mental health system induced trauma. This trauma is usually what makes us as consumers passionate, but it is often retold in CAGs in a way that can be re-traumatising for the person and the other consumers in the room. Often, when we ask for consumer perspective, consumers think that means they should talk about all the trauma, the denial of basic human rights and the abuse they have endured in the system. We want to make sure that no one thought they were expected to share those dark times.[19]

Safety: It is important that CAGs are safe places; dissuading people from competing about who has endured the most gruesome service encounters is necessary, as is understanding that this is a product of cultures of service delivery and public consultation which reward drama. For some people, to be real and worthwhile, is to be dramatic and they are systemically taught this, so it is incumbent on CAGs to prefigure the changes they want in service delivery by practicing the ways of relating in CAGs and learning how to do this respectfully.

Support: Being appointed to a CAG is a big deal for many people; some are intimidated and some will be rebellious. All will need the chance of consumer supervision, by experienced consumer leaders, with a good grasp of the critical consumer perspective. There is a lot for some people to learn and support is necessary, but it is the *relational* aspects of the work which will be the most challenging. Past experiences will be retriggered in many different ways and for many different reasons. Some responses will

not resonate with others. Passion drives strong views which mean sincere and driven politics, but passion can also bring pain. Much of what we know is hard learned and competent supervision is invaluable. It should be properly funded from the beginning of a person's tenure. Relationship with a consumer consultant needs to be regular and for sufficient time; as one CAG member noted:

"It's reassuring to know that you are travelling well within the CAG before each monthly meeting comes around." VMIAC CAG day, November 2014

Supervision: Supervision is not just about emotional support; it offers members a chance to discuss issues they have with others on the CAG with a mind-set of resolution: challenging communication, careless language, dominating or diminutive style, personality preferences, chairing practices, or parts of personal style that may bug others. This is about learning and about reclaiming a sense of self; a growing confidence in choices and decision making; starting to see glasses as half-full instead of half-empty; recognising competency in ourselves and feeling OK about one's contribution to the CAG growing with competent supervision.

Training: Timely, quality training is essential for all CAGs; sometimes it might be offered by consumer experts in a variety of areas. These might be substantive or content-based or might be about process; it might be skills or knowledge specific to the organisation or specialist knowledge outside the reach of the consumer body of knowledge.

In any CAG a range of educational attainment levels will be present, but competent educators will use this to the entire group's advantage. Specific training needs to be available for new

appointees, or it might be offered to one or two members from different CAGs. This might be vital in content areas that are a bit out of the normal, but important nonetheless and facilitating this learning, back into the respective CAGs, will be important.

There are substantial differences between *education* and *training*, the latter focusing on immediate skills and competencies and the former focusing on things like developing critical thinking, about the consumer perspective, or developing a 'sixth sense' for recognising subtleties of language, used in everyday mental illness settings, which ought to be thought about more critically. Role playing, of common scenarios consumers are involved in, can challenge CAG members to move through difficult situations differently.

Having a central calendar of education and training for the year may be useful, so that everybody knows what will be on and how to plan for it and to reduce unnecessary duplication. An annual forum, bringing together consumers from across Victoria and – later – from interstate, would enable an increased pool of learning experiences, in an exciting but safe environment. Consumers will be able to ascertain what their group has in common with other groups and explore what is done differently.

Victorian CAG Website: Another suggestion is to facilitate conversations on-line and to set up a website, to enable greater flexibility in communication and learning. Interactivity is possible and will enhance learning for many. Sharing information and ideas across and between well-established and developing CAGs is vital. Information about developments can be obtained from the Victorian Mental Illness Awareness Council (VMIAC)[20]. Directory maps and details about different CAG groups would

be invaluable, relieving isolation and creating opportunities for people to move from CAGs to consumer consultancy and/or other positions within services.

Knowledge

Martin and Cross nicely describe '*lived experience*' as *field expertise*;[21] its educational aim would be to enable CAG members to recognise their knowledge as expertise and, as such, it is vital. Without doubt, many will be challenged by others: '*you are just running your own agenda*', '*you aren't representative*' (as though you possibly could be), '*you're elitist*', '*you're not typical*', '*you're just political*' and it has always been thus. Having confidence in one's field expertise and critical consumer perspective to field such challenges competently is, in good part, learned.

As CAGs become more mature, as members feel safe in their positions and as organisations build trust, they will start to assert their knowledge collectively and individually. Portfolios and new leaders will emerge from the CAG; they will need to learn new sets of skills in managing, asserting, recording, note taking, feeding back, arguing a case for the CAG, setting agendas and understanding different roles and responsibilities. Some members will already have these skills but others will be on a, sometimes, stressful learning curve.

Leadership skills and training are also vital and need to be part of the calendar of events; new leaders emerge in very different ways, some of us are born to be managers and some are not. Leaders might never want to manage people and they don't have to; they can lead as good citizens, public speakers, educators, academics, role models, debaters, influencers, thinkers, writers, culture carriers or specialists in field expertise.

Sometimes it's a matter of skills and techniques but often, education for leadership is about *learning how to redefine ourselves.*

Launching Pad[22]

Like the NCAG before, the structure and function of this generation of CAGs is to be enablers, to enable people to jump off into any number of activities that improve health, support other consumers, earn incomes, increase morale, demand respect, drive change for others and help combat the shame and grief that often accompany a diagnosis of mental illness or/and a life of trauma, neglect and/or abuse. These new ways of being in the world will be, in good part, *relational* and will not be empowering because of the largesse of a service or a clinician. Such pursuits might include more committees within the organisation, working with people (paid or unpaid) within the organisation or the community sector more generally or in the local shopping centre. Joining the full- or part-time workforce inside or outside the sector or getting safely on the speakers' circuit, talking about personal experience or what needs changing in the mental health system. CAGs have multifaceted possibilities for the group, the organisation and the individual.

Individual Knowledge

CAG members don't only bring different types of skills, interests and priorities; they also bring different knowledge, insights and understandings. The consumer movement is not monolithic; people can have very different positions based on, for example, lived experience of child abuse or having lived a secluded life, or a lived experience of physical disability, of poverty, of being bashed by a partner or of totally incapacitating repeats of

depression. This is the nature of experience – it covers a litany of possibilities.

The challenge for a CAG is to both understand, respect and honour '*lived experience*' and to direct priorities in a way that fulfils the needs of the organisation or service without curtailing its responsibility to proactively pursue its own CAG agenda.

Accessibility

> "*Don't go over the heads of local consumers because there are local conditions and differences that are important.*" Consumer VMIAC Forum, November 2014

It's important for CAGs to be respectful of people's different needs in terms of accessibility of written material and in making sure they can join in conversations without being intimidated. People have vastly differing levels of education; many consumers have fallen from a great height and their grief and shame is palpable. Too often consumers are treated as if we have an intellectual rather than a psychiatric disability and we are patronised. Everyone needs to be thought about compassionately and be able to make vital contributions in the way they best can.

Specialist Knowledge

The reality is that consumers have a unique body of knowledge[23], powerful, commanding of attention and essential to understanding mental health systems and practice. The importance of our body of knowledge and the role of CAGs is illustrated below using a technique called a Johari Window[24]. Traditionally, services and organisations were blind to the many important insights consumers

have and could share; knowledge remained in silos where groups of consumers shared their insight between themselves and others essentially '*outside the system*' and in ways institutional culture could not readily understand and was mostly not interested in taking on board. At the same time, organisations and services have in the past seen consumers as the fodder of services, as people *to be done on and done to*[25]. Even when consumers are conceptualised as at the centre of service delivery[26], they have mainly been seen as actors in their own recovery journey. The knowledge and service delivery wisdom remained within the service or organisation and its staff.

With the advent of a peer workforce and the development of CAGs, the potential for cross-fertilisation of knowledge emerged. With consumers educating services and staff and the possibility of organisations to filter important intelligence back to consumers, the large area of unknown, potentially harmful service delivery or personally catastrophic possibilities decreases proportionally[27].

Specialised CAGs

CAGs are still in their formative period; nobody really knows their potential or the full range of possibilities. We know that it sometimes works and sometimes flops when we try to artificially create '*inclusive*' CAGs. We also know that some people and some groups don't want to be part of CAGs, for any number of reasons and finding alternative ways to hear from them is essential; many other mechanisms might be utilised productively. Nonetheless, possibilities for specialised CAGs should be considered; e.g. Youth; Regional or Rural; Gay/Lesbian; Aboriginal; CALD; Age/elderly.

There is also a possibility for short-term or limited-time CAGs around specific issues; these may last a year and, for example, feed into a large organisation such as NEAMI or MIND or may be State-wide or region-wide clinical CAGs. They are more substantial than committees and subcommittees and tenure would be for one or two years, with the option of ongoing status

Diagram 1: Before advent of Peer Workforce and CAGs

in some circumstances. The sorts of issues that might need long-term consideration by a dedicated group of consumers might be:

- People accepted by the National Disability Insurance Agency giving advice to that body;

- Advice to the Victorian Mental Health Complaints Commission;

- People who have been refused services in the public sector or have experiences of needing

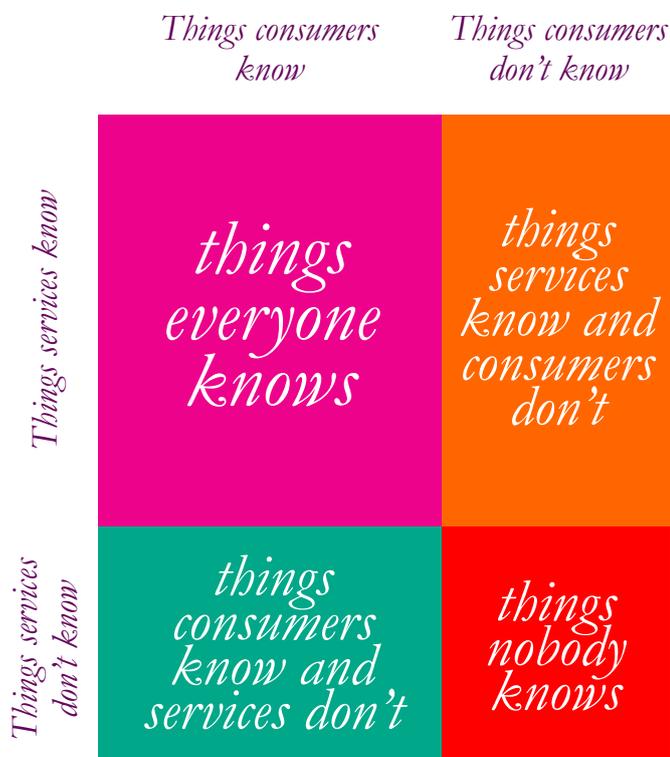| Things consumers know	Things consumers don't know
Things services know — *things everyone knows*	*things services know and consumers don't*
Things services don't know — *things consumers know and services don't*	*things nobody knows*

Diagram 2: After Peer Workforce and CAGs

private clinicians but had public hospital admissions. Such a CAG would be well-placed to advise the sector on service triage and the work of the new advocacy and complaints commissions, intake procedures and what could improve at the nexus between public and private services.

Celebration / what works

Sometimes it's good for consumers to celebrate; so often things go wrong and no one listens to us and we feel tokenised, patronised, infantilised and even insincerely valorised. Despite all this, we still have the strongest consumer peak-body in Australia and we do have the longest history of activity in the non-government (now called 'community') sector. In Victoria, we also have a better history of consumer participation, at least trying consumer-led interventions to infiltrate cooperative, industrial, bureaucratic and professional stupor. We have a history of consumer consultants going back to 1995. With all its problems, this history is worth celebrating. Below are three comments made by CAG members at the planning day, held at VMIAC in November 2014:

"It's interesting how the CAGs evolved from something that felt tokenistic to when it demanded to be taken seriously".

"When they [the organisation] is actively anti-oppressive there is a potential for liberation."

"Occasionally, we get something through and achieve change – enjoy it, celebrate it."

Conclusion

To feed into and work with organisations and services which expect consumers to only be interested in their own personal journey remains a challenge. Consumers know so much that services need to learn. It is shocking that initiatives, such as the development of CAGs, didn't happen years ago. CAGs are part of a jigsaw of consumer initiatives and activities that fit together, to enable services and organisations to do their job better. With the insight and rigour of a critical consumer perspective and its body of knowledge and with the goodwill of services and organisations, we may look forward to a brighter future, for those the latter are meant to serve.

Endnotes

1. In this chapter I draw heavily on two resources; first, 'Working toward genuine consumer participation: Why CAGs don't work' by Leah Martin and Jacinta Cross, published in Our Consumer Place (OCP) Newsletter, August 2012. The second resource was an exploration of how a dedicated website might help local CAGs, run at the Victorian Mental Illness Awareness Council (VMIAC), moderated by Flick Grey, Wanda Bennetts and Catherine Roper, held on 20th November 2014.

2. Our Consumer Place, MadQuarry Dictionary p. http://www.ourcommunity.com.au/files/OCP/MadQuarryDictionary.pdf

3. They were first known as staff-consumer consultants, a legacy of a consumer research project which was looking at mechanisms to enhance staff capacity to hear and learn from the experience of consumers.

4. Wadsworth Y (ed.) The Essential U&I (2001) Victorian Health Promotion Foundation, Melbourne

8. 'Supervisors' is a very difficult word for some consumers as it implies a hierarchy. Perhaps 'co-visors' might work but at some point we should cut our linguistic losses and recognise that the concept is worth pursuing even if the language is not.

6. Consumers employed by the organisation in a number of roles relevant to improving the quality of service delivery, changing service culture, educating clinicians, making sure consumers are well informed, enabling feedback from consumers to services about the quality of their services, coordination of consumer activity between different sites of an organisation, education and training for consumers, management and internal and external committees and groups as well as research from a critical consumer perspective and sometimes work with campaigns, human resources, external contractors to the organisation, boards and senior committees.

7. Critical consumer perspective does not mean being critical of everything. It means glancing a sceptical eye over what one views, not taking things at face value but asking questions and looking for 'why things are so'.

8. Wadsworth, Y. The Essential U&I, Victorian Health Promotion Foundation, Melbourne 2001; Epstein M. 'Understanding and Involvement (U&I) The project concludes... 1995 p ?

9. Melbourne School of Health Sciences, Department of Nursing: Co-production http://nursing.unimelb.edu.au/consumerinvolvement/keywords/co-production

10. There are big questions around representation as a concept, especially when people don't have the time, finance and or skills to represent truly. There are also questions around the utility of the concept as it seems to be at odds with ideas of 'lived experience' which suggests individual specificity.

11. See Our Consumer Place book on Mad Meetings p.17 http://www.ourcommunity.com.au/files/OCP/MadMeetings.pdf

12. See Our Consumer Place book on Mad Meetings p.17 http://www.ourcommunity.com.au/files/OCP/MadMeetings.pdf

13. See Interviews with consumer/survivor leaders at OCP http://www.ourconsumerplace.com.au/resources#interviews and "Deep Insight: Leaders in the International Mental Health Consumer/Survivor Movement share their thinking" http://www.ourcommunity.com.au/files/OCP/DeepInsight.pdf

14. Martin, L. and Cross, J. Working towards genuine consumer participation: Why CAGs don't work; p.5 http://www.ourcommunity.com.au/files/OCP/Aug2012.pdf

15. Gordon, S. 2014 Health Issues Centre Journal; Shaw J. and Epstein M. Lemon Tree Learning Book, VMIAC

16. Wadsworth Y, Building in Research & Evaluation Human Inquiry for Living Systems, Allen & Unwin 2010

17. Wadsworth Y, Do It Yourself Social Research page 17, Allen & Unwin 2011

18. See Our Consumer Place book on MadQuarry Dictionary p.17 http://www.ourcommunity.com.au/files/OCP/MadMeetings.pdf

19. Martin L. and Cross J. Working towards genuine consumer participation: Why CAGs don't work; p.5 http://www.ourcommunity.com.au/files/OCP/Aug2012.pdf

20. VMIAC, Building 1, 22 Aintree Street, Brunswick East, 3057, Victoria, Australia Phone: (03) 9380 3900 | Fax: (03) 9388 1445 vmiac.org.au

21. Martin L. and Cross J. Working towards genuine consumer participation: Why CAGs don't work; http://www.ourcommunity.com.au/files/OCP/Aug2012.pdf

22. Term adopted from Martin L. and Cross J. Working towards genuine consumer participation: Why CAGs don't work; http://www.ourcommunity.com.au/files/OCP/Aug2012.pdf

23. I first came across this important way of understanding our place in mental health in a talk by Catherine Roper. It is important because it moves our contribution from vessels of story only to important purveyors of a unique, shared critical consumer perspective knowledge base.

24. The idea of a Johari window was created in 1955 by two American psychologists, Joseph Luft) and Harrington Ingham. It can be adapted as a learning technique in many different ways.[

25. A concept I first came to in Yoland Wadsworth's, Do It Yourself Social Research, Allen and Unwin 2007

26. See Our Consumer Place, "Why I don't want to be piggy in the middle" Newsletter October 2012 p 6 http://www.ourcommunity.com.au/files/OCP/Oct2012.pdf

27. It is important, however, for all involved with CAGs to remember that the Johari Window does not build in the fact that different knowledge has different amounts of power, acceptance and authority in medical and community culture. This is something CAGs need to keep in mind.

{ *Consulting with Groups
of Consumers* }

Merinda Epstein

Consulting with Groups of Consumers

Consultation (noun): They've already made up their minds before they get through NSW. So by the time they get to WA they're just mining us for anecdotes. *MadQuarry Dictionary 2013 p. 8*

Introduction

It has become currency for those who work in the 'system' - governments, bureaucracies, public inquiries and private instrumentalities - to seek to consult with groups of consumers. As an ever-growing number of consumers are drawn to the sector as workers, they too are charged with consulting with their constituencies. Indeed, there is generally an insistence that consultation is central to the work if they are to properly 'represent'[28] those they serve. Despite the limitations of consultations, there are ways of consulting with groups that are better than others and experienced organisations in the consumer sector have historical wisdom that is special and substantial.[29]

'Stakeholders'

Consumers should never be seen as sausage-holders in the consultation process; the language of '*stakeholders*' employed by those conducting consultations with groups of consumers is deceptive. Wadsworth describes consumers as the *Critical Reference Group* (CRG) (1997). Although this is a mouthful it is important; we all know processes where the voice of a whole group of consumers translates into one set of notes whilst discussions with five '*influential others*' generate five additional sets of notes and then are reported about as if they have equal value and numerical strength; this is not equal treatment nor is it democratic. So the 'size' of the stake is important.... Further,

consumers are often not 'stakeholders' in their own lives; there are multiple dependencies to take into account which deny our power as 'stakeholders'.

Consultation: The Process

Having established that consulting with groups of consumers is fraught, it is perhaps also necessary for consumers to be informed about the ways consultants, be they 'others' or employed consumers, go about this process.

1. Negotiating the Consultation

External Consultants: companies and sometimes community organisations win tenders to conduct consultations with groups of consumers mostly brought together for the purpose; sometimes they are required to consult with established consumer groups. Whichever, the ethics in regard to practice and to negotiated contracts needs attention; sometimes contracts are drawn-up with consumer organisations that can do the consulting 'in house', having infrastructure, resources and experience to conduct consultations in a timely and cost-effective way.

The contract is frequently made with the lowest commercial bidder; a company/organisation able to make such a bid can - either - be sagacious and efficient – or - because they don't understand the consumer imperative - or - because they're cutting costs to win the bid and skimp on the provision of safe, useful, timely, properly funded collection of consumer experiences and expertise. Consulting

is *always* political; choices are made by both contractor and consultants about who matters most and who must be seen to matter most; hence, tokenism is always a possibility.

From the long list of attributes and experiences required in the tender, the imperative to consult respectfully with consumer groups (and groups of consumers) frequently falls back into a pack of other interests. Knowing how to listen to distressed and powerless, angry and disillusioned, silenced and sometimes shrill people is not prioritised; other specialist skills are not demanded. It is wrongly assumed that these competencies can be learned 'on the job' by non-specialised consultation firms; organisations, governments and instrumentalities that want a good job completed have a responsibility to ensure that competent inquiry is mandated in the bidding documentation.

Organisations/governments employing consultants: Especially during times of economic contraction, there is a responsibility for organisations to determine that sufficient money is available to consult with consumers and consumer groups, in a democratic way and respecting that they are the critically important group. Such consultations need to be uniquely centred, to ensure consumers are heard when they are competing with 'experts' perceived to have authority.

External consultants may require education, sanction when necessary, clauses in the contract, employed consumers to guide them and help them understand the sector, including warnings about valuing different expertise selectively and shining a light on consumer accomplishments, the importance of the critical consumer perspective (Grey 2014) and the consumer body of knowledge (Roper).

Tendering organisations need to monitor a tendency, amongst outside consultants, to make (often deprecating) judgements about the 'quality' of knowledge of groups of consumers, based on spurious (community and sometimes sector) assumptions behind notions like '*serious mental illness*', '*real patients*', '*grassroots*', '*the most vulnerable*', diagnostic categories, elitism, '*levels of functioning*', '*professional consumers*', or even chronicity and recovery. Such notions are often mischievously introduced by people having their own agenda – 'others' and sometimes consumers. External consultants often have very little knowledge, or even the independent capacity to be critical about what is presented to them as '*common sense*'.

Expert consultation firms are sometimes attracted to tenders because of personal experiences of mental illness in the family life of senior staff; mental illness as perceived by family and friends *is not the same* as mental illness understood/experienced by (groups of) consumers. This disconnect can, sometimes, lead to a witches brew of half facts and half-truths, as carers and family members hear consumer groups selectively and filter everything through a 'carer' lens. Although family members and 'carers' have a valid point of view, *they are not the Critical Reference Group* and they have a great deal more power and status than many consumers. Many external consultants, unfamiliar with the sector, will fuse the family/carer/ consumer perspectives. History has taught us that this, on its own, can derail a consultation process. It is essential that tender processes be overt and gauge the perspectives of the central consultants who will work on the project beyond their formal qualifications and experience.

Consumers: Increasingly, consumers are being asked to consult with 'their group', 'consumer groups', 'consumers in groups', service user groups and Consumer Advisory Groups. The way the process is articulated and then carried out is important; for example, we can 'hear' things in undemocratic ways when processes are run without sufficient funding. This doesn't mean that you can't find out what '*people truly think*' more cheaply; with goodwill and knowledge, a lot is possible! It does mean that when groups negotiate with the organisations undertaking the consultation, they should make sure that the money is going to the right places so that consultants can make ethical decisions about methods and priorities. We also have a responsibility to educate the services and agencies we work for about good practice[30] and consumers about what is acceptable in terms of giving time and effort to help organisations, governments, instrumentalities find out what they want to learn.

Because of life and service history, many people diagnosed or labelled with 'mental illness' don't fully appreciate they can say 'no'; they don't always realise they don't have to talk in the first person, that they can demand - either - confidentiality – or - to be named if they want to make a proud statement to the world; *either is their prerogative*. Sometimes groups prefer a group identity rather than individual ownership of particular group wisdom, which fundamentally is a democratic stance. Along with proper, respectful funding, such macro-issues need to be negotiated with consumer consultants' organisations *before* the consultation; playing catch-up on substantial matters rarely works.

2. The Process: The Variables

It's impossible to offer a recipe for consulting with groups of consumers; a first variable is whether groups are established and affiliated with an organisation or whether consultants pull in a group of people without any real '*groupness*' other than being in the same place at the same time and having a shared investment in mental health provision.

The group created for consultation[31] may be a group of people with *experiences* of being diagnosed or labelled with 'mental illness'; and/or a group of people who *identify* as being diagnosed or labelled with such; and/or people who identify as *carers* of people diagnosed or labelled with 'mental illness'; and/or a group of people who identify as *healers* of those who are labelled with or diagnosed with such; and/or... Although becoming a 'group' for the purpose of the consultation, we may be more or less 'pure' in the sense of our distillation of experiences of 'mental illness;' the group experience of consumers on their own is very different to that of consumers being together in a group with family members, clinicians and administrators.

The above groupings have different amounts of institutional power, arguably those of consumers the least. As well, in such artificially created 'groupness', different axes of social and institutional power cross: social class, illness, race, sexual preference, education, disability, gender, ethnicity, diagnosis, poverty, professional status, position, experience of the world, command of English and capacity to tell a heart-wrenching story. Such sets of political relationships offer complex combinations and are daubed in power differentials generated by personal connection.

As intimated before, the most powerful probably won't be part of a group anyway; they will most likely get the consultants' ears quite separately, maybe over dinner, the previous or following evening, possibly including (some) consumer(s).

Groups connected through organisational affiliation; this might mean local groups connected as satellites of a consumer organisation, for example VMIAC; or groups that are part of a community or a community mental health organisation. The consultation process is either run by consumers (if it's a group supported by a consumer organisation) or sometimes by 'others' (if it's a group supported or affiliated with a health or community organisation that does not have a consumer workforce.) Organisations supporting a consumer workforce might have the inquiry run by consumers. Sometimes governments and their agencies engage the community sector or consumer organisations to consult with 'their' groups on their behalf.

3. The Process: Time, money – macro considerations

Beyond careful negotiation with the funders of the consultation, it is important to ask specific questions about what is most important for the people for whom the service/group/organisation/committee exists:

How much time and money have we got? What can we realistically do with the time and money that we have? (examples only)

- Do we most want to speak to consumer groups or bring groups of consumers together? What are the pros and cons?

- Is it most important to spend this money travelling to as many consumers as we can?

And/or

- Can we sub-contract out the collection of data to consumer groups to collect information for us? Payment? Catering? Travel? Report writing? Any down sides? *And/or*

- Is it most important to employ consumers to provide a critical consumer analysis of the findings or to work out whether our filtering, of what we thought we heard, was the best we could possibly do? *And/or*

- Is it most important to ask really deep, telling, and provocative questions of a small group of consumers who have really thought about the issues we are exploring? *And/or*

- Is it most important to tape and transcribe, so we hear the small voices and the detail that might surprise us and that we might miss otherwise? *And/or*

- Is it most important spending money to advertise in electronic ways to get to groups of young people? Or a wider slice of the consumer population? Or specific populations of people with 'mental illness' or...

How much of our decision-making is/must be political?

- Does the funding body need us to demonstrate to 'stakeholders' that we have been 'thorough' – i.e. 'been seen' all over the place' and having spoken to as many groups as possible? Is this sound practice from a critical consumer perspective?

- Are there groups who will 'scream' about not having been 'consulted'?

- Are there individuals who have the power to cause problems if their wishes/ideas are not overt in the report? Do they have pet groups?

- Are certain groups more available? For example affiliated to a peak body or easily accessed by an organisation? What's the ethics of this?

- Are some groups seen as more 'core' to the public mental health agenda or core to some other political agenda – pharmaceutical companies, for example? Ethics again?

What is the relative visibility of some groups or persons invited to a consultation?

- What about people who are locked out of public services?

- What about people who are told they are 'bad' and not 'mad'?

- What about people who have a lot to say but totally refuse any sort of psychiatric intervention?

- What about people who use GPs or private services?

- What about people who support each other, using relationships in the community?

- What about people who simply wouldn't relate their struggles to anything personal at all – they see them as social and political?

- What about minority groups; e.g. GLBTI or CALD or Aboriginal, young or old (examples only)?

- What about groups that fit into categories we don't like very much; e.g. support groups around different diagnoses; groups supported by medicalised agencies or sponsored by drug companies; twelve-step groups or groups that oppose all forms of psychiatry?

- Does 'chasing-down' minority and hard-to-reach groups also have a negative edge? How much value do consumer organisations get from the effort outlaid and is there a risk of devaluing minorities' and hard-to-reach groups' refusal to be involved in processes that they consider a waste their time? Whose agenda is it?

4. Collective Wisdom

Over the thirty-plus years that the consumer movement in mental health has been active, we have learnt a great deal about consultations – sometimes by getting it wrong, or by not understanding the political agenda or, simply, by not buying in the skills that were needed. It has become obvious that there are (at least) four ingredients to involving groups of consumers in human inquiry:

> *"People [diagnosed with 'mental illness' are 'the experts' about their own life and being. [They] carry the wisdom to best articulate their own needs if they are accorded the time, space and means to do so."*[33]

- Understanding the importance of the Critical Reference Group;

- A critical consumer perspective;

- Skills in inquiry, questioning with open questions which allow deeper exploration;

- Time and money to allow people to best answer questions for themselves and in their groups without feeling hassled or 'used'.

5. Some useful information gleaned from experience

Insights about method: People who have not been listened to and who have had a history of horrible things written about them need notes that are taken to be transparent, preferably written in front of them; they need an opportunity to see they have been recorded accurately and a good process to correct wrong interpretations.

- Consumer organisations/groups know through group experiences how to consult. This expertise is rarely appreciated or actively sought. From things as simple as understanding smoking culture, to appreciating the importance of consumer subculture, groups tend to be an underutilised resource.

- Consumers often need tables in front of them, both to take notes and to 'hide behind'. This is important for many people who have had their realities challenged and have experienced demeaning 'therapy' and

  programs requiring chairs in horseshoes and mortifying embarrassment.

- Bringing groups of people together creates challenges. People recover in their own way. People have different experiences, politics,

families, tolerance levels and education, experiences of shame and grief and priorities determined by their own struggles. Sometimes we can finish each other's sentences and at other times we disagree and shame each other. These disparate needs must be understood and valued as part of 'real lives' and real group dynamics.

- People who haven't been listened to by services may clamour to be heard in consultations; people may tell and retell their stories until they feel heard [34]. This creates opportunities for consultants to demonstrate their listening skills and lateral thinking. Respectful approaches to different listening need to be built in and handled well, especially considering other consumers may get frustrated.

- People have been indoctrinated in the ways of 'clamour-hearing' in mental health services - dramatizing stories to outdo each other is not pathology and is not dishonest. It is a pattern that works in services which are blind to subtlety. Seeding it in consultation is a skill.

- Ideally, consumers should be able to see that their words have been interpreted accurately but sometimes taping and transcribing is not possible, so consultants need to demonstrate their integrity in another way, the operative word being '*demonstrate*.' Talking at consumers about the integrity and past performance of a consultancy firm, for example, doesn't cut it.

- Nobody is a truly objective scribe; e.g. someone volunteering to collect a group's discussion on butcher's paper might be well intentioned, benign or manipulative. Consultants need to think about this.

Allocating a '*silent scribe from outside*' is maybe the best we can do, with a least disruptive process for people to say "*No, that's not what I said*".

- Not everything that is useful is an anecdote of 'mental illness' or 'psychosis' or services or... Some people speak through narrative but others don't. It's important to hear both. This also means that analytical consumers might, but don't necessarily, know more than those who prefer narrative. It's a style difference and not necessarily a difference in content or import.

- Trawling for anecdotes is lazy consultation; experienced consumers know which ones work and have a cache that gets used and reused.

- Transparency in consultation recording is vital. For people who have been watched to within a cell of their bodies, have had terrible judgemental words written about them and don't trust processes of recording their opinions honestly in consultational integrity. Consultants tapping away on their notebook computer and creating notes for their eyes alone is not good process. Consultations need to be safe and this isn't safe for many.

- Taken to an extreme, the process of correcting mistakes in interpretation strengthens the loudest and further silences the quietest. This dynamic must also be taken into account and the skills of those who are creating a listening and respectful environment become more important.

- If you come to a group of consumers ostensibly to listen and end up *talking at* people instead, you'll get short shrift from the old campaigners and no response when you eventually inquire from others. A consultation implies listening and not talking more than necessary.

- There is one exception to this; the method of inquiry employed in the *Understanding and Involvement (U&I) project* emerged as researchers found that people needed relationships and conversations to enable their opinions to form and find oxygen. Before that they were intimidated into not believing they had anything to say. As the consumer researcher had a relationship with other 'patients', people did start to speak and speaking nearly always turned into a gush of things that were previously being self-censored and dismissed as unworthy. Conversations between consumer consultants and people in acute units, for example, don't constitute '*bias*;' rather, they enable. In the U&I project, conversations were recorded and returned to consumers to be approved before being written up in the book as a conversation, with the researcher's and the 'patient's' voice both prominent.[35]

- People get frustrated by different things; don't ever just listen to the frustrations of those with most power to articulate their needs.

- Executive summaries almost never summarise the contents of consultations with groups of people. They simply repeat the special interests of someone, usually not a consumer, who has already had too much to say.

Consumers working *'in the system'* only get to be or talk with or learn from those who have not been 'gate-kept' out of the system, got away with refusing psychiatry completely, or who use private services or primarily GPs. These groups are too often absent from review and their views are lost to the system.

- Outside the public system, consumers have almost no voice. Organised groups are often captured by medicalisation, drug companies, health insurance companies etc. The voice needs to be heard; how to do it with integrity is the question.

- Don't ever go to consult with a group without a way to record people's responses. If you want to go to sell a message, don't say it's a consultation. Consumers develop very astute detectors of bureaucratic nonsense.

- If people (including consumers) really want to know something, it is often better to drill down with a small group of consumers who have thought about it than waste the time of a large group of consumers who haven't thought about it and perhaps don't want to.

- People '*not-knowing*' is worth recording. People change their minds in the group process and this is also interesting. Sometimes, we come to understandings only as we start to say the thing we thought we believed and it was found wanting in articulation.

Groups of consumers, carers and clinicians: Joint Consultations

- Combined groups of consumers, service providers and carers must have a different purpose. It's important consultants know what they want and from whom. Bringing groups together as a cost saving effort will not work.

- Neither carers nor clinicians are the *Critical Reference Group*; maximum effort must be made to enable the voice of consumers in mixed groups.

- Sometimes carers and clinicians make a song and dance of 'listening' to consumers first; this is just a different way of wielding power. It doesn't matter how many times you speak if the 'listening bit' is an 'act.'

- Sometimes clinicians feel silenced in such groups; they don't know where they stand and in particular, our allies don't want to take over or speak for us. It's important for consultants to give permission for our allies to say what they need to say.

- On the other hand, some clinicians will just demand an audience elsewhere and they will, sure enough, be heard; the ethical question for consumer groups and organisations is: should we follow suit and demand a separate audience and what are the consequences thereof?

- The term '*lived experience*' merges the voice of consumers and carers, which may be a real problem for consultations.

- Power relationships in groups are of paramount importance for consultants and they must actively engage in these; joint consultation groups should, at least, have comparable numbers of Consumers, Carers and providers/clinicians/workers/managers.

- Many carers are consumers and many consumers are carers; what is important is the perspective from which they choose to speak

and that they do so from the *right premise*. 'Carers'/family members say (often privately), *"we have only a little bit of mental illness. My daughter has Schizophrenia and it's disrespectful for me talk about my depression in this context".* What is the agenda behind this and what does it mean for mixed group consultations and what are the ethics of projecting one lot of suffering on to another? Group dynamics must deal with this with integrity; hearing from the *'most vulnerable'* by giving the *carers* of 'the most vulnerable' a lot of air space is suspect.

- Many clinicians are consumers; they must speak as clinicians if they are clinicians *for the purpose of the consultation*. Clinicians who are not 'out' as consumers can not have a critical consumer perspective (Grey).

- We all need permission from our relatives if we want to use their stories; consultants can and must monitor this. This goes both ways and is actually very hard; without permission, both consumers and 'carers' need to tell their story in a 'bubble' and sometimes we simply can't tell our story without implicating others.

- Some carers are so desperate to be heard that their stories are drama. It is really important that consultations don't turn into carers telling more and more desperate stories. This is not about their right to be heard but rather that it silences smaller but important stories from consumers and other carers. Probably this applies to some consumers as well. Is it about group processes that demand the dramatic in order to be heard?

Consultants' Perceptions challenged

- There is no such thing as a 'real' consumer; no-one's experiences are more real than anyone else's.

- Whatever 'mental illness' is, people make decisions about the degree to which they identify with this aspect of their lives; whether for specifically political reasons, community acceptance, self-esteem or any other reason, it's a person's own decision how they choose to spend time and with whom. Groups that work are self-selected.

- Being 'out' as mad, crazy or loopy is also an individual choice; no therapist, clinician, community member, person conducting a consultation has a right to pathologise people's right of association.

- There's no such thing as *Serious Mental Illness* defined by diagnosis; diagnoses are used for public service gatekeeping and many people don't find talking about diagnoses at all useful; many clinicians don't find diagnoses useful either, but those in the public sector are forced to use them.

- Many consumers prefer to use the term 'experiences' rather than the medical term 'symptoms'.

- We are all (potentially and pragmatically) both grass roots consumers and consumer leaders; these are never two different groups.

- People who use private services are not by definition stupid or co-opted or '*not real consumers*' or lacking the grunt to get out of a trap they are not locked into. Generalised commentary on psychiatry by groups lacking input from the private sector and GPs is deficient.

- People who hate psychiatry or don't find it useful, who criticise radically, who call forced treatment 'torture', who critique power arrangements in psychiatry, who distrust medical imperialism and who find answers in the community or alternatives are not radical extremists. Generalised commentary on psychiatry by groups lacking input from the anti-psychiatry lobby is deficient.

- Many consumers are understandably annoyed by tokenism; when consultation after consultation with groups of consumers changes nothing, people become apathetic. Who can blame them?

- The most fundamental group for many people is 'the family'; people labelled with 'mental illness' who are obvious in the community are often not the only member of the family to be diagnosed with a 'mental illness' or have a 'mental illness' that is not diagnosed. It is a myth to believe that families are always normal and that the person with the mental illness is the unexplainable anomaly.

Research/Evaluation[36]

People often call all groups that are formed to collect information '*focus groups*', a misuse of this term. In this chart Yoland Wadsworth identified the difference:

Group Interviews	*Focus Groups*
… as old as groups and inquiry	… originated in the late 1950's out of market research
… may range from unstructured to more highly structured (a series of questions)	… orient around a single issue or topic
… may be naturally occurring groups; on site groups; recurrent/longitudinal groups; representative groups	…group of strangers who meet once only at researcher's venue
… size can range from 3 to ??? (public meetings may be 100s or so)	… size 4-12 (6 – 8 favoured)
… range in formats (e.g. Delphi, nominal, planning, therapeutic, advisory, action, brainstorming, consultative, indigenous etc.) depending on purpose	… single format and purpose (to explore range of views or experiences around a single matter/topic)
… participants may be homogenous or heterogeneous	… participants are homogeneous on the single topic
… participants may discuss, plan, agree, rate/disagree, rank items, problem-solve, as well as collect views	… participants only give their views
May operate as a quasi-survey	… can never operate as a survey
Researchers as questioners	… researcher as moderator

Both Groups…

- Data derives both from individual views and from the effects of group interaction;

- Best to go for concrete experiences and perspectives, rather than abstract attitudes and opinions;

- Data are the transcripts of the discussions;

- Data is voluminous!

- Analysis needs creative thinking.

Endnotes

28. Consumers now have a strong critique of the concept of 'representation' in many contexts (see Our Consumer Place book on Mad Meetings). Although the critique is primarily concerned with 'others' (Grey 2012), demands for consumers to 'represent' also applies to employed consumers' acquiescence to demands to represent others and justify it by poorly thought-through or tokenistic consultations. Representation of groups of people, or even a class of people, is usually not possible given the resources available to consumers regardless of whether we are employed in the system or not. The nature of 'lived experience' is that we carry our understandings, hurts, freedoms, politics, grief, shame and childhoods with us regardless of how many other consumers we may or may not have spoken with. We sieve all new information through our own particular experiences and that is not necessarily ameliorated by consultations no matter how good the process. Denying this will make it worse.

29. A snapshot of this is the Victorian Mental Illness Awareness Council (VMIAC) and the capacity to attract group members to be bothered sharing their opinions by sausage sizzle technology. That is: (1) The questions have to be worth answering; (2) The venue needs to be conducive to sharing a consumer perspective; (3) Ideally consumers need to be the question askers; (4) There needs to be provision for smoking; and (5) food is not a bribe, it is respectful.

30. See Our Consumer Place publication Mad Meetings http://www.ourcommunity.com.au/files/OCP/MadMeetings.pdf

31. See table at end of this 'chapter' by Yoland Wadsworth

32. Questions that can't be answered by a simple yes or no

33. Developing Effective Consumer Participation in Mental Health Services: The Lemon Tree Project (1997) VMIAC.

34. Wadsworth Y. (ed.) The Essential U&I, Victorian Health Promotion Foundation, Melbourne 2001.

35. Wadsworth, Y. (ed.) 2001, The Essential U&I Victorian Health Promotion Foundation

36. Yoland Wadsworth

• Do It Yourself Social Research, Wadsworth Y. 2010 Allen & Unwin Sydney, Australia

• Every day Evaluation on the Run, Wadsworth Y. 2010 Allen& Unwin, Sydney, Australia

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How Consumers Can Make the Most of "Time-Limited Groups"

Allan Pinches

How Consumers Can Make the Most of "Time-Limited Groups"

This chapter offers examples of time-limited groups, identifying advantages and challenges as such "special and finite" entities engage with a multiplicity of problem solving/solution seeking tasks in the mental health field, where more hierarchical approaches have not succeeded.

Time-limited groups in the mental health sector have many beneficial aspects – sometimes including the very fact that they *are* time-limited, as this often means that they are under pressure to "get the job done" without delay and to keep highly focused on key objectives. These objectives might take the form of overseeing or co-designing plans or strategies for developments within mental health services; a time-limited group might be a stakeholder reference panel for a systemic change process, which may include consumers, carers, clinical services, Community Mental Health Support Services and other organisations.

Being time-limited does not need to equate with being ineffective – in fact, many small 'steering committees' or 'taskforce' power-packs of energy can and often do provide breakthroughs relatively quickly, because of their added flexibility, autonomy, freedom for creativity, removal of hierarchy, operating in a more "*decision-free zone,*" experimenting without sanctions of "failure" and capitalising from team bonding.

Another important element is the potential for an 'advisory' or 'steering group' to be able to co-design, oversee and help process consultation and feedback processes with consumers, carers, services and other stakeholders about a range of issues and developments and to ensure that the consultation is high quality, inclusive and authentic. As there is a growing interest in consumer and carer views among service providers and a growing common language developing about improving practice, in line with recovery-oriented services, peer support and a range of partnerships, time-limited groups may play an important role stepping in such consultation roles.

Flexibility and involving leading "knowledge holders"

Time-limited groups and committees can often process matters at levels above and beyond the more constrained practices of the public service. They can, however, also be stymied by under-funding, vague or inadequate terms of reference, conflicting demands, extremely rushed timelines and deadlines and securing strongly committed and deeply knowledgeable membership, possibly making it difficult to influence change and development.

Importantly, the time-limited set-up can mean that the best available "*knowledge holders*" across a wide area are more likely to be able to be involved, as their involvement will likely be shorter and defined. Indeed, such groups can bring people to the table, with knowledge about particular issues in processes of deep dialogue, which can assist in bringing changes to the system to some extent. For all of the unfortunate headlines and strange and sometimes stigmatising views in the community,

in recent years, the mental health sector has been something of an exemplar of change-oriented participatory democracy and the consumer movement has played a large role in this.

Committees and other time-limited groups can be very interesting and creative places, leading to genuine innovation and change (and sometimes even friendship and fun!). The idea that committees are dull, irrelevant, boring and pedantic or that "*the camel is a horse created by a committee*" are somewhat unfortunate and misleading; they are an important part of the "*engine room*" of society, in government, business, or community contexts – and many challenging and rewarding processes are taking place.

Examples of time-limited groups:

Some examples with brief descriptions of time-limited groups follow:

- **Special consultancies including Consumer Consultants:** Research/Development/Evaluation projects with linked sub-committees of Consumer Representatives, playing the role of liaison agents with primary consumers at local services (e.g. substantial RFV consumer participation scoping project in 2000; the NEAMI Consumer Participation and Leadership Audit in 2010.[37])

- **Focus Groups:** Generally meeting in small groups (see previous chapter), often as part of a research or evaluation project, covering a range of shared issues, facilitated using closed-questions, testing particular propositions/options/proposals/comparisons. (see Y. Wadsworth's suggestions about evaluation in the previous article)

- **Critical Reference Committees:** Groups advising on research or evaluation projects, aimed at holding them to respond, authentically, to the key values and stated needs of the populations being researched/evaluated. Membership would be from the groups of stakeholders being the 'subjects' of the research/evaluation: either consumers, family/carers, GPs, community leaders, service staff, etc.

- **Workshops:** Generally small groups of people intending to examine and discuss issues of interest, facilitated in an open and participatory way, encouraging the dynamic generation of ideas/solutions/insights and understandings. Whilst there may be 'input' given by the facilitator or via presentations, the emphasis is on all participants' contributions and the strength of their discussions.

- **Project or event steering groups:** Overseeing and guiding the development of conferences, programs, campaigns or courses; usually representations of all intended or hoped for stakeholders is assured as well as the necessary combination of requisite skills to run the event or project (consumers, staff of relevant agencies, government representatives, etc.)

- **Advisory Groups:** Consumer Consultants, specialist staff, departmental representations, NGO representatives, etc. providing specialist advice for service provider project development, preparation of project funding applications, service re-design, etc.

- **Planning days – Strategic 'Think Tanks':** e.g. in support of longer-term Consumer Groups or Organisations, including Consumer

Advisory Groups in Mental Health services (see previous chapters). Could include performance evaluation or the examination of emerging problems/constraints for groups or programs, the consideration of strategic aims and objectives, new projects, resources, avenues of support, etc.

- **Consumer Peer Support groups:** an emerging feature of some Mental Health service settings, group sessions often revolve around information provision to promote better community access, sharing life stories, shared problem solving from lived experience, guest speakers, informal social gatherings, the latter as important as the formally organised occasions.

- **Search Conferences:** often organised as a short-term and time-limited event or meeting intending to develop an agenda for existing groups or programs or policy development, e.g. for CAG groups or for group needs assessments, feeding into a new program or to develop a Lived Experience Workforce or a training calendar or planning fundraising activities.

Some considerations regarding the participation of consumers in time-limited groups:

- Consumer membership in time-limited groups is important and needs careful consideration - members need to have genuine interest and knowledge about the key areas being dealt with. Having interview/discussions with proposed participants can help make clear duties and expectations, and involve the person in the decision making about this.

- A varied mix of skills, backgrounds, lived experience, vocational backgrounds and areas of interest among consumer-workers can be brought into groups; principles of Experience-Based co-Design and variants of Participatory Action Research are important methodologies to assure appropriate and expert contribution by consumers.

- Consumer representation from "socially diverse" areas of the community is essential (e.g. CALD, gender and GLBTI, ATSI, cross-disability etc.). While local members of such constituencies would be preferable, if necessary, recruiting from relevant organisations should be considered if the former are not available.

- Sitting fees for consumers participating in committees, including time-limited ones, are widely acknowledged as best practice. Amounts of such fees are low (e.g. $20 - $25 per hour during meeting time only and generally not extending to preparation or follow-up) but consumers remain fearful as to their effects on Centrelink payments. Voluntary attendance at meetings – whilst useful as learning and confidence-building opportunities – should remain the exception.

Some practical tips for time-limited groups:

- Time-limited groups are usually fairly task-oriented and tend to rely on a careful balance of structure, content and process.

- The facilitation style needs to be creative and flexible: knowing when to encourage discussion to fan outward and when to encourage it to be drawn in. A variety of group

work modalities can be used in the discussion and to process issues, including a mixture of warm-up games, role plays, visioning exercises, etc. and ideas created can inserted into the aims, objectives and outcomes of the group process. Warmup exercises are numerous and readily available from a range of electronic and hard-copy sources.

- Matrix-building exercises on key issues (using a variety of questions/matching statements resulting in participants standing in quadrants corresponding to their "positioning" on an issue and in proximity to people sharing similar views).

- Brainstorming; whiteboard/butcher's paper exercises in plenary or in small groups; table-top discussions and small-group breakout sessions, followed by report-back by group nominees;

- Strategic Questioning; a range of participatory decision making methods.[38]

Getting Strategic; some suggestions for involvement

Strategic Questioning is a straightforward but powerful method of social inquiry and problem solution-seeking readily adaptable to many types of group work; the approach has been developed by social change activist Fran Peavey. Its strength is that it encourages creative and original thinking as it strips away pre-programmed assumptions and conventional thinking, bringing each matter back to basics. This involves an appeal to personal responsibility in relation to making practical differences, to a range of social, economic and environmental issues.

Peavey wrote extensively on Strategic Questioning, much of which is easily found on the web and in her Strategic Questioning Manual[39]. The approach would typically begin with: "*What would it take… for you/or a specific community to make a difference to… [the problem or issue.]?*"

Yoland Wadsworth's "*Human Inquiry for Living Systems*" is another resource for creative forms of Participatory Action Research methodology in social inquiry; the latest version of her thinking appears in her most recent book[40] which also draws from her consumer consultancy work in the landmark Understanding and Involvement Project (U&I) at Royal Park Hospital, from 1989 to 1996, in ongoing collaboration with Merinda Epstein. The extensive series of project reports drew strong parallels between PAR methods, consumer participation, the growth of the consumer movement, the development of the recovery paradigm and the PDRS sector which followed de-institutionalisation.

Wadsworth's book deals extensively with "*building a culture of inquiry*" into organisations and in the ways groups (including limited-time groups) are run and facilitated, particularly when applied to mental health consumer participation, evaluation and community-based Participatory Action Research. The implementation of thought-through methodological structures in group processes, whilst applied more specifically to evaluation and research projects, can inform those readers who need to organise time-limited groups for any purpose in the Mental Health sector:

- detailed principles for research, evaluation and more generally, working in complex human service organisations, when viewed as "living systems";

- sequences and examples of "research cycle questions" which can be creatively harnessed in working towards "intelligent systems" which could also become self-adjusting; and,

- promotion of the development of more (truly) human services, partly through service providers being encouraged to open up to listen carefully and without flinching to the expressed hurts, unmet needs, and creative thinking of consumers.

The Importance of Setting Clear Terms of Reference

Formulating Terms of Reference (TOR) is especially important for time-limited groups and discussions to design and influence this stage are important. The setting of TOR can make or break a project in terms of its working structures and processes and poorly-drafted TOR based on certain pre-existing biases are barriers to democratic expression and social justice.

- Time-limited groups need to have a "real purpose", which its members really want to translate into reality and that the organisations and communities behind the groups want to happen.

- It is important that a project should have "*key deliverables*" set out in writing from the beginning.

- There should be a step-by-step plan drawn up, stating the aims and objectives, stages of progress, progress reporting intervals, who is responsible for what actions, accounts, insurances, contingency plans etc.

- Aims and Objectives are important elements to be set early in exploratory styles of group work, as a continuing touchstone for group processes.

- It is important to allow adequate scope for development and room for discovery in limited-time group – but to resist allowing processes to stray outside of the defined purpose (i.e. "mission creep" can happen from a group's idealistic and in some ways understandable urge to solve all the problems and issues it identifies "*in one grand sweep*.")

- New "break-out" questions or areas of likely discoveries can be set aside for later examination, in a bracketed list of suggestions for further exploration – "offcuts" -- might be useful; such notes can be filed away and could be used towards future funding applications.

Meeting Ground Rules:

Setting agreed ground rules/guidelines for the group can also be helpful in time-limited groups. While these sometimes may run to a long list, principles associated with "*Treat each other with respect*" will often suffice. Consumers and others - by and large - are capable, as adults, to show courtesy and respect to others and lots of goodwill exists within the consumer movement.

Ground rules should not be too onerous or have connotations with distrust; however, if it seems likely that a more elaborate setting of ground rules might be needed for a particular time-limited group – if particularly contentious issues are likely to arise or if group members request more comprehensive ground rules - it can be helpful to assist the group to work through additional ground rules. *This process in itself can be a terrific warmup exercise for the group.* Finally, *housekeeping matters*; e.g. toilets, smoking areas, coffee and tea facilities, local key landmarks such as public transport hubs, etc.

Some typical ground rules may include:

- Treat each other with respect.

- Please do not interrupt or "talk over" someone who is speaking.

- Indicate by hand to the facilitator/chair that you wish to speak and speak in the turn indicated.

- Discussion and difference of opinion are normal occurrences at all kinds of meetings and emotions are all human; however, for the sake of the group's functioning, it is important that members try to refrain from expressions of anger or personal abuse.

- It is of prime importance to respect the person's "*lived experience*."

- Different people have a variety of tolerances to things like swearing, violent terminology, discriminatory language, etc. and these need to be avoided.

- Address the issue – not the person.

- It's wise to remember that people are individuals, as well as being interested in "consumer matters" at a meeting. In many ways, the consumer movement can be seen as a diversity of diversities and a cross-section of many parts of society. This is often a "good thing" – not just another reason for vigilance.

- The group might have other suggestions.

If any member or members find themselves in a situation of emotional distress, for whatever reason, they may request:

- an adjournment of the meeting for a short while, for a "smoko" or coffee break and have some wind-down time;

- they can talk to the facilitator or co-facilitator (or relevant staff members) to clarify how they see the issues and the direct impact on them, based on their experiences or those of others;

- if appropriate, two participants who may have come into conflict, may wish to make peace/ or apologise/or in the spirit of cooperation, promise to each other that for the greater good, they will think about what the other said. If the facilitator is at the centre of a conflict, they need to take a similar path. Other options might be suggested by a group.

- It is critically important that if a consumer participant suddenly takes flight from a meeting, that they should not be simply "allowed" to leave the premises, without being given the opportunity to de-brief or at least clearly state that they will be OK. Other meeting participants may tend to worry about them otherwise and there are very real and critical duty-of-care implications. Transport arrangements, or encouraging the participant to contact a trusted friend, should be considered.

- Some committees can develop problems. On some committees relating to large projects or several linked projects within mental health services, sub-committees or special task groups can start "multiplying like amoebas" and some caution may be needed for the tasks not to become too dispersed or the project losing direction.

Endnotes

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Deakin Workshops: pioneering groups moving toward co-production — a personal reflection

Merinda Epstein

Deakin Workshops: pioneering groups moving toward co-production—a personal reflection

In the late-1990s, in the wake of a nationwide push to create, in public psychiatry settings, multi-disciplinary clinical teams, a project was auspiced under the National Mental Health Strategy (NMHS). Throughout Australia, services were being let down by clinicians who didn't know how to work well together and without the skills or the inclination, the newly created community teams were too often dysfunctional.

Bureaucratic Background:

Previously, the Australian Health Ministers Advisory Council (AHMAC), through the NMHS, had twice unsuccessfully attempted to drive a project around collaborative practice and clinical education. There was a high level of frustration; consumers and carers refused to accept the role of '*extras in the cast*' and clinical groups, representing constituencies with power to lose, found this new frontier unpalatable. Both these projects nosedived into political scrums and intellectual malaise.

The Organising Committee

If we learned anything at all from the two previous attempts, it was that this work was important, complex, necessary and all about power, both real and perceived. The strength of character of the organising committee for the third project was going to be vital. It would need very senior and respected clinicians and clinical educators and it would need feisty, knowledgeable, progressive consumer educators who knew each other and could work as a power base that could stand its ground.

Of great interest, both within this committee and within the larger group involved with the workshops, consumers were invited on the basis of their expertise in education and training and clinicians were expected to represent a constituency. This was the direct opposite of the usual circumstance then and still today; it was a major breakthrough. The message was that we were expert educators with pedagogical knowledge and they were representatives, bringing to the discussion the opinions and views of the organisation they were expected to represent.

As with all national projects, the capacity to meet in person was limited, which was a pity; we understood very well the fate of previous attempts at this task and the need to steer this one through to a result that was useful to the sector and to the government.

The Vision

The Organising Committee shared a vision of creating two-day workshops, meeting over a period of time; the former consulting group, 'Deakin Human Services' was contracted to run them. The idea of the project was, in part, to prefigure inter-disciplinary relationships, including relationships with consumers and carers we would expect in service settings.

The structure of the group

Prefiguring Practice: In order to realise our vision, we worked with the consultants to structure the learning group, deliberately factoring in power relationships by determining that each clinical group would be represented by academics from within their discipline and clinicians representing the major associations and colleges within the sector. These included the College of Mental Health Nursing, the Australian Psychological Association and the Royal Australian and New Zealand College of Psychiatry (RANZCP), for example. The purpose of the decision to include the clinical colleges was twofold:

> **1.** To maintain the determination that clinical educators and clinicians should represent the power blocs within the industry and, therefore, maximise the chance of 'take up';

> **2.** To try to inculcate new priorities in education into post-initial, college-based, training.

Critical mass: In order to keep the consumer voice (and the carer voice) loud enough to be heard, it was decided to limit numbers in each clinical category to five, resulting in five expert consumer educators, five carer educators, five psychiatric nurse educator academics and/ or representatives of the College of Psychiatric Nursing; five clinical psychologist academics or representatives on the APS, five social work academics or representatives of the Australian Association of Social Workers (AASW); five academics in the field or psychiatry and/or representatives of the RANZCP and occupational therapy academics or representatives from the Occupational Therapy Council (Australia and New Zealand).

Group Guidelines: in order to skew taken-for-granted power relations, other guidelines were put in place.

- We insisted that membership of the group was closed; if 'busy clinicians', for example, failed to prioritise the workshops, they would not be replaced and the voice of their affiliate organisation would not be present.

- We deemed from the beginning that professionalism in relation to emotion would be that passion and hurt and caring would all be welcomed. This was new to many who had been taught that professionalism meant the exact opposite.

- From the beginning we observed that there was a weird sense of humour percolating through the group, resulting in clinical factions (as they saw themselves) putting each other down behind the backs of others. We deemed that when the different clinical groups assembled separately, there would be a *consumer or carer process watcher* looking out for the conduct of the group especially about '*bitching*' about other disciplines. The process watching part of the workshops also asserted the rights of consumers and carers to be important players as mediators in the mental health system, reminding others what was and what wasn't central.

- Along with encouraging emotions, there was a clear understanding that problems should be dealt with within the group and not leave the workshop unresolved. Again, we hoped we were structuring the workshops to prefigure sound collaborative practice.

Emphasis on pedagogy

Another different emphasis of this project was the intense focus on pedagogy, on the process of *how* we learn as much as on *what* we learn. An expert educator from Flinders University who had an interest in the education of clinicians was invited to all the workshops and reported back at the end of each day on the learning that was and wasn't taking place. He was a vital inclusion of the group and was, like the process watchers in the small group, a witness to good and bad collaborative and relational personal and clinical affiliate interactions. He fed back regularly about the '*hidden curriculum*' as he saw it: the covert or 'silent' learning that takes place, often outside the formal curricula intentions.

Good teachers know to listen for it, uncover it when necessary and understand it in relation to their teaching. The issue of the hidden curriculum is major, primarily given the power differences between the groups within the whole. As he was someone in a powerful position of authority in the academe realm of the most powerful group (School of Psychiatry), his position, we hoped, would be taken seriously by all.

Emphasis on collaborative practice

The task set by the NMHS was to explore ways clinical groups could adapt to working in teams that respected different clinical knowledge and strengths, worked positively towards shared goals, were mindful of power, included consumers and carers as 'equal partners' and respected the uniqueness of each professional group. The starting point was that most undergraduate education occurs in clinical silos and many practicing clinicians have very little idea what their colleagues actually do. Secondly, clinical groups have more or less power to determine how they practice and this is mitigated by managerial hierarchies. The degree of threat to status and power in the new arrangements was directly related to the power of the group under existing conditions; for example, *generic casework* was a challenging concept for clinical psychologists.

Deakin Human Services attempted to create a group environment in these workshops, where members would have to question taken-for-granted assumptions about their own clinical group and its place in relation to consumers, carers and other clinicians.

The Structure of the Workshops

The cluster of 5 weekend workshops at the Australian National University (ANU)

- The initial two weekends were designed to offer a power boost to consumers and carers for the coming weekends. One weekend was for consumers from around Australia to come together on their own to strategise; we discussed power and tactics and our own vision; learnt about each other's' strengths, weaknesses and interests; talked about our backgrounds as educators, formal and informal; found out about personal style, some of us being more '*in your face*', others more reflective and considered. We knew we needed this weekend to enable us to start the workshops from an equal place on the grid as the professional groups. Despite consumers collectively being the most qualified in teaching and learning disciplines, we knew we would carry little institutional authority without the boost of an extra weekend enabling us to claim capacity and agency.

- The next five meetings were whole-group weekends at ANU University House; the architecture of the building, a quadrangle around water, helped build rapport amongst people from all clinical groups, its age and the beautiful wood in the rooms being especially important for consumers. The slightly isolated position with a lovely restaurant and somewhat quirky special dining hall were important. Even though mobile phones couldn't be banned and technology was not evenly spread across participants, the temptation to continually dash out for impromptu coffee meetings about content supposedly more important was kept to a minimum. The green surrounds and tranquillity of nature was important although still being in central Canberra.

- The fact that we were accommodated together as a group and that we met, ate, slept and walked together in the quadrangle was significant as was the big effort made to ensure that the professional clinical representatives both had a constituency and remained constant as individual participants. Basically, we really got to know each other which cut through the power differentials and maintained a nuanced balance between an individual as, e.g. as a psychiatrist, but also as someone developing a loyalty to 'us' as a group of educators.

- The first joint activity was to play the *Lemon Looning* board game[41], a deliberate attempt to stop the clinical representatives in their track and say: "*What consumers know is knowledge. This knowledge is not just relative to individual experience. It is group experience. It has substance. It is teachable. It is a fundamentally different and important perspective which you have shown you don't*

understand; now please sit down and listen to us and get this straight before we start."

It was a deliberate attempt to start with pedagogy that was unfamiliar to many, for some very stressful and infantilising - even excruciating; a few became very embarrassed, believing we were making fools of ourselves with a game that didn't work. Thankfully, we were not drawn into this largely because the instructions of the game teach consumers how to deal with others' inevitable patronising. Without the initial consumer weekend, some consumers may also have become uncomfortable.

Amongst its many purposes, the game is *meant to* make people feel embarrassed and uncomfortable, 'aping' as closely as possible how people experience services in this sector. Real learning is often uncomfortable; the more 'scientific', powerful groups were 'stumped'; they struggled with the activity and wanted to abandon the tool, but group pressure kept them at the table. As the first activity over which they had little control, it set the scene for interactions in the group for the following weekends; not only empowered this consumer voice; we also demonstrated clearly the personal exposure, embarrassment and power-over of certain practice approaches. We knew that many clinicians would not handle this very well and they didn't and we were able to feed this back to them in the group setting.

Reflections on the five weekends

For their time, these were amazing weekends; sadly, they happened before their time. In brief, the following aspects seem worth mentioning:

1. Unfortunately the psychiatrists voted with their feet and didn't return after the first two group workshops. Those who stayed the distance were already committed to

consumer leadership and known to be 'good eggs.' In a very moving and important moment, one psychiatrist, prepared to show his vulnerability, burst into tears, saying he believed he was being picked on, that he had little power in reality, that he, too, hated the system and that in our culture, it was hard for psychiatrists too. The group surrounded him with the power of a group to heal, but consumers (gently) stood their ground and reminded him that he did have a lot of power and needed to acknowledge this. It was a fantastic learning moment for the whole group.

2. The psychologists struggled, although the same dynamic as with psychiatrists occurred, whereby the educators who were most consumer-perspective aware 'hung-in', again, those working in the public sector with a joint academic role being the ones understanding the critical consumer perspective.[42] Our request, '*education for real collaboration*,' was difficult for some psychologist-educators working from very traditional, isolated and competitive models.

3. Not surprisingly, the groups most openly, self critically and wholesomely participating were psychiatric nurse educators, consumers, occupational therapy educators, carers and social work educators. Nothing was easy in these workshops; we would have been disappointed if it had been! Educators from all disciplines were being challenged as professionals, educators and as people by groups over which they previously held enormous power. At times, even the most receptive groups struggled, those professionals looking for answers with consumers and carers rather than being defensive being rewarded. They moved

to a position where 'not-knowing' was OK, a significant step forward.

4. On one occasion, the consumers staged a united walk-out; even with the structures and processes put in place to enable consumers to attend the workshops as 'equals', things went wrong. Situations where consumer knowledge was disregarded and process handled badly by Deakin Human Services still occurred; slipping into appeasing power blocks is very easy in such situations, but we needed to make a stand and collectively say, '*this is wrong*'. We did it using the only mechanism available – removing our goodwill and then our presence. The move had the intended effect; business stopped and the group dynamic for the remaining workshops changed.

The Structure of the Report and how it reflected the group

The report was written in many parts; the core group at the workshops had decided on four basic recommendations[43], strongly consumer-perspective oriented and driven by the strong carer voice. It was at that point I started to worry; the process which I thought had been good may have been flawed in ways I didn't or couldn't understand at the time. I believe the report was path-breaking; each discipline as well as carers and consumers had the autonomy to write their own chapter, Deakin Human Services writing the introduction, the description, the literature review, the analysis and the conclusion, thus reflecting process and group dynamics. The psychiatrists' chapter was fabulous, but only two psychiatrists were left standing by the end of the workshops. Nonetheless it is a permanent record of an honest attempt to make radical changes to the education of psychiatrists and the institution of psychiatry.

The chapter reflected the group struggle. A substantial issue in the group itself and the report was that the 'calamity' of status collapse was not important for consumers and carers but loomed large for clinical groups, a dissonance that persisted.

Problems:

In spite of being funded by the NMHS, the Federal and State and Territory governments through the Australian Health Ministers Advisory Council (AHMAC) would not publish the report; eventually, it was published and attributed to Deakin Human Services, after intense background lobbying.

1. None of the recommendations were ever implemented; we put this down to the project being before its time as every effort was made to build it in to medical sector unions and associations, governments at State and Territory Level and schools of Medicine, Psychology, Occupational Therapy, Mental Health Nursing and Social Work. Perhaps resentment about the process or hidden fury at the prominent role of consumers at work or a reflex from established power bases.

2. The fact that carers have considerably more power than consumers was never problematised.

3. Some clinical educators and some groups were much more experienced, confident and competent at working with consumers than others; although consumer leadership was in its infancy, it was obvious that educators in mental health nursing and occupational therapy were much more prepared to be challenged by articulate and passionate consumers. Stereotypes were challenged and some seemed able to learn from this whilst others floundered.

4. Having lobbied hard to be included, the community sector was furious at what they perceived as being 'left out'; however, from a process point of view, it was imperative for consumers that they were not there. With every added professional group, the consumer voice is one part more diluted and they fought to keep the number of players down to the five main clinical groups. Deakin Human Services understood in a way others could not that, in order for consumers to be heard, some groups had to miss out. We knew they would get their opportunity in a way consumers might never again.

The winners:

The winner from the meeting of this group was *relationships*; although no formal recommendations were implemented, powerful ties were established through people being together to achieve similar goals. For example, Brenda Happell (now Professor of Psychiatric Nursing at University of Canberra) and I came away energised and friends, scheming how to create the first dedicated Consumer Educator position in Australia, a position directly resulting from the Deakin *process* (rather than being its *product*). Other abiding friendships-across-discipline-borders grew and flourished and in many ways marked the serious entry of consumers into the clinical education landscape.

Endnotes

41. Available from the Victorian Mental Illness Awareness Council http://www.vmiac.org.au/ but must be sessions run by fully trained consumer educators and must be used in education sessions that are funded to employ a critical mass of grass roots consumers. This is a highly sophisticated tool, nuanced and designed with multiple learning objectives. It holds its capacity through time and is still a pedagogically sound tool given the conditions carefully notated in the instruction book. It is not a toy.

42. Critical Consumer Perspective is used similar to 'critical theory'; it simply means analytical, well informed, logical – more than simply individualistic storytelling.

43. See Wendy Weir's Summary

http://www.google.com.au/url?sa=t&rct=j&q=& esrc=s&source=web&cd=1&ved=0CCgQFjAA&u rl=http%3A%2F%2Fwww.recoveryinnovations. com.au%2Fuploads%2F9%2FDeakin_summary-pdf&ei=0cqQVM2LCtX m8AXU0oHwAg &usg=AFQjCNHnFbJVFVoia5V_CzxLhN-z3Exumg&bvm=bv.82001339,d.dGc

{ *Deep Dialogue Groups* }

Merinda Epstein

Deep Dialogue Groups

During the 1990s, the Victorian Mental Illness Awareness Council (VMIAC) trialled the idea to co-create with mental health institutions conversation groups emulating and learning from the power dynamics of institutional practice. We wanted to better understand and explore solutions to the tensions, contradictions, communication mismatches, language limitations and discursive fault lines in communication between services and the people who use them, particularly those forced to use them.

The idea of *Deep Dialogue Groups*[44] was developed through two consecutive projects over seven years: the Understanding and Involvement (U&I) and the Lemon Tree Learning Projects. The groups were experimental and we all learnt a great deal from them, also from things which went wrong and from our mistakes. Dynamic groups can be set up with great care for detail and co-production, but sometimes the design itself is adversely affected by the power differentials the groups were set up to explore. This was particularly apparent in the second comprehensively evaluated Deep Dialogue Group trial. They might not have worked as we wanted, but even with all the mistakes and parts we would do differently next time, it remains an interesting idea.

Deep Dialogue Groups bring mental health clinicians/workers/service providers together in a room with consumers/patients to meet regularly to enable 'deep dialogue', 'beyond the ordinary', 'beyond the cursory', 'beyond the formulaic', 'beyond the established power relationships', 'beyond the prism of social and professional roles', indeed, beyond the prosaic, instrumental

and politic. We got to this place incrementally; in the first stage, researchers in the U&I project (Understanding, Anytime[45]) the project team acted as conduits to bring information and knowledge from consumers to staff and then back from staff to consumers, the two groups not being in the same room.

From such position of lack of trust we hoped to create groups in which it was safe to be raw and to *not know*; where questioning was more important than answers; where staff felt safe from bosses, administrators and consultants; where attendance wasn't worth marks and everyone came because they wanted to; where every person was there because they saw a misfit between the practice they experienced and the one they wanted to experience, *between what is and what ought to be* (Do it yourself social Research[47]). We wanted to see if it was possible for groups of staff and consumers to be genuine, explorative, withholding judgement, labels and medical paraphernalia, to notice truths and sit with them, to notice power and sit with that too. We hoped that the groups would be structured in such a way that different and in many ways

antagonistic discourses could be in the room together, the group dynamic allowing the minority discourse to be heard.

History

The idea of Deep Dialogue Groups grew out of a major project undertaken by the Victorian Mental Illness Council in the 1990s, the *Understanding & Involvement* (U&I) project, an attempt to build-in dialogue between service providers and users in an acute hospital setting. Deep dialogue groups were part of a collection of different 'mechanisms' trialled by the project, the fundamental idea being that, in order to achieve the necessary balance of power, these groups needed to be *consumer-driven but staff collaborative* and that we would trial and evaluate them. The concept was revisited a few years later as part of the *Lemon Tree Lemon Project*. The two efforts were similar in name but quite different in realisation; it is interesting to place them side by side and see what they achieved and where they struggled. They were to inform later attempts to create non-decision making groups that still survive within a sector often under funding stress and suffering from competing ideologies.

In the beginning… the Steering Committee

In the beginning there was a committee; like many projects before and after, the collaborative committee started off as a steering committee, but with a difference. An effort was made to fill it not with one each of various categories of staff, administrators and consumers, but rather to invite people from areas of service participation who already were supporters or allies. A '*liquorice allsorts*' committee, allowing us to tick-off all the boxes and pretend that '*all important minorities were included*,' did not appeal to us.

The justification for this process was two-fold; *first*, we used the '*divining rod principle*': we believed that those bending the rod with their enthusiasm and demanding inclusion were likely to see the distance out and that those co-opted, often reluctantly, would end up finding excuses not to come, wouldn't understand our process and would be liabilities rather than assets, no matter who they were and how much power they wielded. The *second* principle was about not playing institutional games. We had already done the hard yards guiding a consumer project through research and ethics committees. After that we enlisted our known clinical and administrative allies to steer this project with us from that point.

Next… the Collaborative Group

The meeting format let us down; regular meeting structures with a chair person, agenda, minutes and strict order didn't work. With the degree of enthusiasm in the room, the urgency to get on with the task of relating to each other through our differences in position and discourse tugged. We found we were just getting to the meeting's substantive best, when the chair felt impelled to stop the dialogue and bring us back to order and the agenda. After a few meetings, everyone was unhappy, so we changed it. As a research project, we wanted to collect our wisdom and turned the Steering Committee into a Collaborative Group, recording and taping the meetings which we extended from one to two hours. It proved

the making of the project; by turning the role of participants from committee to group members, the project was blessed with invaluable insight from administrators, consumers, clinicians, a non-government organisation, a community visitor and two nurse educators – all of whom attended because they wanted to see the way the institution operated change. As we had been careful to maintain a majority of consumers, the power of their voice was enabled; indeed, several consumers were surprised how much they had actually said and how attentive the group had been to their suggestions when reading the transcription of the discussion.

The Collaborative Group becomes a Deep Dialogue Group

Because of the success of the collaborative group, a decision was made to widen it to include more people and remove the layer of research; as interesting as it probably would have been to tape and record the jostling of discourses in a many-faced, larger deep dialogue group, it was logistically impossible and may well have stopped some people from talking – probably affecting staff more than the consumers who were, on the whole, thrilled to be heard at last and wanted to share insights garnered over many years.

The *deep dialogue* group emerged as part of the development of a need for *three sites* which would together maximise the opportunity for

services to improve as a result of feedback loops between patients and staff; the following '*sites of intense activity*' were identified:

- **Decision-making sites:** the sites we all probably know the best – they usually look like 'familiar' meetings and behave bureaucratically and predictably; Flick Grey has come to call them '*Other People's Committees*';

- **Consumer-only sites**: sites where we have the opportunity to unite, plan, strategise, organise, gain critical mass and prepare for times when we will be relatively powerless; and

- **Non-decision making sites (deep dialogue groups):** where 'real' discourse can occur and time does not have to be wasted making decisions often handed down by others.

Deep Dialogue Groups Rules

We wanted to test the idea that we could develop a structure that would allow for the deep conversations taking place between consumers and service providers to continue. Importantly, we developed a set of rules how deep dialogue forums would be conducted; they were not to structure the process into rigidity, rather to test what we had learnt in the U&I project and would enhance meaningful dialogue between consumers and clinicians.[48]

50% consumers and staff	More consumers (to even up the power imbalance), if deemed necessary in the early stages.
Consumer-initiated & perspective facilitated	This also may mean consumer-chaired or/and consumer organisation facilitated.
Organically grown	Like the town planner, who designs a town square in a place where no one ever gathers and then is dismayed about its lack of use by the community, forums, that are artificially constructed, won't work. Many of us have seen what happens, when organisational 'planners' start contriving a group. The group does not cohere or share a purpose and runs out of steam quickly.
Agenda Free/ single topic	Meetings commence with a single issue, such as medicalisation, prejudice or fear. There is no pressure to get through several items on the agenda, there being no agenda and meetings they are then rather driven by passion for change.
Decision-free environment	What a relief this was for most of us; in Deep Dialogue, no decisions needing to be made. Those discussions that had traditionally been cut short, by an anxious Chair, were now welcome and honoured.
Prefiguring good Practice	People are carefully and actively listened to and people speak until they feel heard; there can be silence, discomfort, repetition of stories and different points of view. People can change their positions and ideas mid-meeting and that's fine. Everyone, clinicians and consumers, get practice in truly listening, with an open willingness to postpone 'observing', 'listening for pathology', 'diagnosing' or explaining, or 'tolerating' using the tools of psychiatry. Sometimes people needed more time to tell the group something and we all had to live with our feelings about this, while understanding that this was less than comfortable for some. It's like we were all practising what we want to see more often in clinical practice.
Chocolate cake factor	Meeting over lunch or tea and cake; sharing food; de-clinicalising the encounter. Props can be used to bring people together, moving us all away from our roles as 'clinicians' and 'patients'. For some reason, homemade food was better for this task.
Location	Use accessible places for staff and an emotionally and historically safe place for consumers. This can be hard to find but those involved in the original U&I Project found it in and around the U&I offices in the hospital.
Continuity of membership where possible	Trust-enhancing. There was an endeavour, to keep the group as cohesive as possible and this meant trying to get the same people there each session. It was hard because, predictably, every other conceivable, competing priority seemed to get in the way.

In Practice

We worked hard to maintain the momentum of the deep dialogue initiatives, but it was difficult for a number of reasons:

- It was difficult to persuade clinicians and managers that decision-free discussions were important; too many people have it in their heads that important groups, in service settings, are there only to make decisions.

- And even when we could attract the numbers, the discussions were sometimes hard:

  - Consumers, needed to tell and sometimes retell stories of bad practice. For many grassroots consumers, storytelling is a fundamental communication tool; people won't stop till they feel heard, for some until some sort of remedial action occurs.

  - Clinicians sometimes felt less comfortable with their own stories, struggling with - what we couldn't help thinking - were archaic definitions of professionalism. Several couldn't help trying to 'help us' (that was their job!), finding it impossible to listen in the way the process required.

  - Clinicians had problems allowing themselves to 'just be' as human beings, with feelings like the rest of us; it was scary, because it could potentially rob them, of the clinical identity that protected them.

  - It seemed to us, that the more consumers needed to tell stories of bad practice, the more clinicians needed to hear stories of *good* practice.

- We were mindful of the fact, that these self-selected clinicians found themselves in the position, of having to hear and re-hear stories of their colleagues' bad practice. Sometimes during the deep dialogue, practitioners felt a need to defend their professional group, or felt unfairly treated because it was not 'their' *personal* practice that caused the offence.

The challenges for the whole group within a deep dialogue context were to:

maintain a capacity to keep asking each other questions and to dig deeper, below superficial explanations or existing understandings;

maintain the ability to continue to not criticise each other and not avoid raising the difficult topics;

sit with silences and give people time to get the courage to speak up;

maintain a *systems perspective* - that is, an ability to see how social expectations operated to 'structure' patterns of action and practices, in ways that could either be experienced as determining or, if aware of them, could be used as levers and pulleys to bring about change;

maintain a reflective space, where energy doesn't have to be immediately converted into political strategy.

The Good News

The good news was that the seminars survived for over a year after the end of the U & I project.

In the end we wrote: "*The provision of a 'space' and the sustenance of a culture of non-*

judgemental, non-decision making dialogue - where the spirit of deeper collaboration and respect is maintained whilst traversing the revelation of pain - remains fragile, tentative but continuing."[49]

The Second Deep Dialogue Project: The Lemon Tree

Unlike the first Deep Dialogue Groups associated with the Understanding & Involvement Project, the second project started when a psychologist approached the *Lemon Tree Learning Project,* with ideas he was interested to explore. This led to a partnership between the VMIAC and the North West Mental Health Service. It achieved a lot, was educational for everyone and cast light on interesting mistakes made by the two organisers – me being one.[50]

It was unusual that a psychotherapist was at the origin of the idea, because we had largely failed to engage either psychologists or psychiatrists (including registrars) in the U&I project. We should have seen from the start that this enthusiastic clinician was well-meaning but didn't actually '*get it*'; but I was blinded by my enthusiasm that 'psychology' was keen to be involved with us – at last.

The process

The idea focussed on a small group of consumers and staff, who would meet regularly, for a limited number of structured group meetings; staff would derive from the same unit (clinical setting) so they could support each other; consumers would be experienced educators and staff would be supported, by a consumer organisation (VMIAC), to act as culture carriers, taking their learning back and applying it in their workplace. The hypothesis was that relational, shared-ownership group processes would enable cultural change, in a way one-off exchanges may not. The process would be evaluated by the consumer organisation.

We were working at the acute end of service provision; consumers had indicated that this was the 'deep-end,' where relationships with staff were most scarred and where most effort needed to be exercised. They also talked about the '*acute unit syndrome*,' where staff saw consumers at their most vulnerable and then extrapolated, from that experience, what it is to be '*someone with a mental illness*'. We hoped we might learn something about this phenomenon and be able to test it.

This was an effort to bring together staff from acute units and consumers, who were very far from being 'most vulnerable.' Consumers were also asked to understand their role as *educators.* This was intended to enable them to take up their power; and we needn't have worried: they had no problem with power!

The Deep Dialogue Group Structure

Two facilitators	One staff member (psychologist) and one consumer (employee of the VMIAC).
Group members	4 experienced and politicised consumers and 4 staff members from the same acute unit (3 nurses and a social worker).
2 moderators-psychotherapists	Psychotherapists: purposely chosen as one female and one male.
Venue	Close to staff but safe for consumers. Eventually the board room at the Mental Health Research Institute was chosen.
No agenda but determination to focus on consumer experiences	Consumers understood their role as educators; so not a simple exchange of views, but rather a mutual exploration of what it means to be a consumer of mental health services.
Conducted over t en weeks	1 1/4 hours, the first weeks consumers with moderators and then staff with moderators.
Questionnaires	All group members were invited to fill in pre-and-post-questionnaires.
Diaries	People were also invited to keep diaries.
Confidentiality	All that was said in the group and in diaries was confidential to the group, excluding the facilitators.
Culture Carriers	The staff members of the group were supported, by consumers, to go back to their unit, with some weight of knowing that there were 4 of them to bring the new learning to their workplace.
Evaluation	VMIAC received a second grant to do a comprehensive evaluation of the group process.

What went well?

- What went wrong also went right; we learned from both, about how to do relational groups in this setting.

- A cursory look at the evaluation shows that all four staff involved did return to their unit with a very strong desire to influence their colleagues. They reported that all being in the same unit was imperative for encouragement and they organised a special staff meeting to raise the issues and a survey to garner what support they had. Considering that they were not senior staff, this is an extraordinary achievement.

- One staff member commented that: "*We want to review issues around seclusion, debriefing, relationships and power.*"

- The culture carrier component slowed down without support from VMIAC, but we expect that the four people involved were personally changed forever.

- "*Evidence, from the interviews, strongly suggests that this process cannot be presented in a one-day workshop format. The key attributes of the process, communication and reflection take time. Staff reported that the time between [the group meetings] gave them an invaluable opportunity to think about issues raised and to make connections between these and workplace practice. To ensure optimal outcomes, in quality improvement, this format is essential.*"

- The consumers very much held their own and, by so doing, challenged preconceptions, not only of the four clinical staff but, also of the two psychotherapists.

- The venue worked for consumers; they loved the massive table and the beautiful wood; the staff were a bit intimidated by the group convening in a boardroom.

The following factors were seen as critical to the success of the project by those consulted during the evaluation.

- The program was collaboratively developed between service and consumer organisations.

- The project was managed by an organically formed Steering Group, consisting of staff, consumers and interested others.

- Implementation of the project in workplaces, where pre-existing awareness of consumer issues, structures for consumer consultation and support from management existed.

- A planned program of sessions held weekly for at least ten weeks.

- Staff who were not forced to be involved.

- Involvement by a number of staff from the same workplace.

- Employing consumer participants familiar with systemic consumer advocacy and issues in mental health services, but not 'representatives' or current/ recent ex-patients of the area service.

- Payment of all consumer participants, for their work and for travel.

What went wrong?

- The psychologist co-convenor, with the best intentions in the world, but also blinded by his own training, insisted that the group be moderated by two psychotherapists.

He probably was thinking of 'duty of care' but, it was totally inappropriate for our purposes. With hindsight, this should not have happened.

- The moderators were psychotherapists; understandably, consumers argued that they were not neutral as they were clinicians and, therefore, there were six clinicians in the room and only four consumers. The therapists were shocked by this candour.

- The psychologist co-convenor met with the two moderators on his own; they had private practices and were difficult to catch and I think we overly regarded their status. We had no idea how he was instructing them and I had suspicions, about his limited grasp of the politics or practice of this endeavour.

- I was not introduced to the two moderators (and never asked to be, to be fair). This was a mistake, as I told consumers one thing and the psychotherapists were being instructed quite differently.

- The convenors, lacking briefing from me, insisted that they meet for two weeks separately with staff and then with consumers, before the start of the group. Consumers, particularly, thought this was a waste of time. This meant that all participants only met 8 times and consumers felt patronised, before the process even started.

- The group started to resemble a rather clumsy, power-down, therapeutic group which was not what was intended.

- Payments for consumers were stuffed-up and they were cross.

- Oh no! The flowers and the cake! At the end of the 8 weeks, the psychologist and I wanted to acknowledge the group. Unfortunately, I am a hopeless cook, having no idea about making a chocolate cake and the one I bought felt inappropriate as soon as I entered the room. It felt like some sort of 'betrayal to capitalism' or, at least, to values we were trying to critique. The psychologist brought flowers for the two moderators who had given time from their respective practices to do this 'work'. The consumers were furious and I knew they would be; they had also given their time. Again, we were giving opposite messages from those we intended; I should have stopped him, or at least demanded we give flowers to everyone. Why didn't I? I was probably intimidated by his position and gobsmacked by his political innocence and betrayal of the very meaning of deep dialogue. I am embarrassed by my failure to assert my convictions.

- Staff did learn a lot and they took it back to their workplace. However, as the money dried up, the consumer organisation support, of the four culture carrier staff and the groups of staff they had developed in the unit, slowed down and ceased after the four month evaluation was complete.

Important learning

- Much to their surprise, those that probably ended up learning most were the two psychotherapists! One of them was sufficiently intrigued to write a paper on the process and present it at a psychotherapy conference. The draft I saw was reflective, questioning and attempted to be true to the process; it was critical of the two facilitators

and of aspects of the process, while striving to understand this strange 'consumer stuff,' with respect but also with cynicism. S-he was referencing internally to therapeutic groups, which was the stumbling block; nonetheless, s-he was committed enough to spend time writing an academic paper, which, unfortunately, was not published.

- Consumers trumped the staff intellectually and conceptually, intimidating a few staff members. One moderator commented: "I thought the consumers were very gentle, though they were sharp with their tongues it is true … given what they could have gone to town about, they were really restrained." Several consumers reported that they attenuated what they said, to make it easier for staff.

- Consumers stated that they were there to inform staff about consumer experience and did not see how this could usefully be reciprocated. One stated: "For us to learn how to be better patients isn't going to help the system."

- It wasn't an even-playing field; staff and consumers said power was an issue, but it was mainly a power differential between the two moderators and members of the group. The moderators were introduced to participants as "psychotherapists" and some consumers and staff expressed ambivalence about having 'therapists' involved in the project. One person commented that one of the moderators got "…so far up my nose I thought [they] were dancing on my brain." S-he added: "The psychotherapeutic gobbledygook just annoys me so much."

Conclusion

Deep Dialogue Groups are an important addition to the group repertoire of consumers; they are places where consumer education meets advocacy, research and evaluation. They challenge the pervasive belief that peak consumer leadership occurs in the decision-making of Boards and the myriad of decision-making committees. They challenge organisations to think again about how to utilise consumer consultants and how to prefigure the way such consultants 'ought to' demonstrate leadership. Deep Dialogue Groups demonstrate the importance of *relationships* as the centre of all practice and all communication in services – a reality that has been endorsed at a national level, but often forgotten at a local level, by clinicians and participating consumers alike. Deep Dialogue Groups have the potential to rewrite policy, putting the emphasis on *learning together,* rather than the usual meeting structure which, too often uses consumers as pawns in a power game not of their making.[51]

Endnotes

44. Deep dialogue groups should not be confused with the 'open dialogue' approach, a Finnish alternative to the traditional mental health system for people diagnosed with "psychoses" such as "schizophrenia". This approach aims to support the individual's network of family and friends, as well as respect the decision-making of the individual. See: http://www.mindfreedom.org/kb/mental-health-alternatives/finland-open-dialogue/jaako_seikkula_paper.rtf/view

45. McGuiness, M & Wadsworth, Y,, Understanding, anytime: a consumer evaluation of an acute psychiatric hospital VMIAC 1991 p.10

46. Note the 'snakes' diagram from' Understanding, Anytime'

47. Wadsworth Y, Do It Yourself Social Research, Allen & Unwin 2011

48. For other uses of 'dialogue' groups, see Westoby and Dowling (2013) for uses in community development and adult education processes; see also David Bohm (2014); Martin Buber and Emmanuel Levinas as well as Paulo Freire are often considered 'parental' to the dialogue approach.

49. Wadsworth, Y. & Epstein, M. Understanding and Involvement (U&I) Consumer Evaluation of Acute Psychiatric Hospital Practice "A Project Concludes...", VMIAC, Melbourne 1996:15

50. Merinda Epstein

51. Mad Meetings, Our Consumer Place; http://www.ourcommunity.com.au/files/OCP/MadMeetings.pdf

{ *The Case for Peer-run Groups* } }

Liz Carr

The Case for Peer-run Groups

The journey so far…

Attitudes and beliefs about "mental illness" and appropriate forms of treatment for people with lived experience of mental health issues or emotional distress have been evolving since records have been kept. The advent in the 1950s of medications as a form of treatment for people experiencing mental or emotional distress marked a major breakthrough leading to other developments.

Following the 1986 introduction of the Mental Health Act protecting the rights of involuntary patients, the Victorian government started to fund community mental health support services, often incorporating consumer groups that had emerged through consumer and carer activism. In the early 1990s, the Burdekin Report provided evidence of the poor treatment and abuse of people receiving institutional care, adding to the impetus for de-institutionalisation. People were demanding to be listened to, complaining loudly about the numerous breaches of their human rights, perpetuated as part of their clinical treatment and many became active in the consumer movement.

The development of a "*recovery*" paradigm in the 2000s and subsequent evidence of the relationship between trauma and mental ill-health has led to a deeper understanding of the causes of mental or emotional distress, paving the way for more appropriate responses to people experiencing mental health issues. This has sharpened our understanding of the importance of people being self-determining about their lives to the greatest possible extent.

Clinical mental health services

While acknowledging the benefits accruing from drug treatments, the past six decades were still dominated by a mechanistic, biomedical view of mental illness, whereby it is said to derive from some "*chemical imbalance*" or genetically-determined issue within affected individuals. The more recent understanding that the overwhelming majority of people experiencing mental or emotional distress have had a history of trauma or abuse is finally questioning this paradigm, as more sophisticated understandings are finally starting to gain traction, often led by consumers themselves.

Whilst pharmacology will continue to play an important role in the treatment of symptoms of mental or emotional distress along with psychiatry more generally, it's never been a popular approach for a very large number of consumers. It is now clear that these medications carry the risk of leading to serious health issues as people with lived experience have a life expectancy 15-20 years less than average. New ways of providing support and treatment to people living with symptoms of mental ill-health or emotional distress need to be explored.

The 2014 Mental Health Act introduced profound changes to clinical service delivery; nominated persons, advance directives, obligatory inclusion of clients in treatment and planning decisions will all enable consumers and their networks to play a significantly more active role in making decisions about and maintaining their mental and physical health.

Non-clinical mental health services

For its entire history, the Psychiatric Disability Rehabilitation and Support Service (PDRSS) sector established comprehensive mechanisms for people with lived experience to join and become part of a consumer group or, a consumer community facilitated by the services. Despite its popularity with consumers, we have witnessed a gradual reduction of this aspect of service delivery over a decade or more and the current recommissioning of services to become Mental Health Community Support Services (MHCSSs) will obviously radically curtail consumers' ability to access opportunities to join with others with lived experience.

Many consumers are distressed about this change, fearing that it will also cut-off their social connections, opportunities and friendships. In its *Pathways to Social Inclusion* series (2008), VicServ provided robust data, demonstrating the vast number of people with lived experience who are disconnected from family, friends or any social network. Why wouldn't people be distressed?

The community mental health sector is now starting to consider the National Disability Insurance Scheme (NDIS) and what it is likely to mean for the future of community mental health support and service delivery in Victoria. We are a long way from being able to predict the new

landscape under the NDIS, but even from this distance, it is apparent that a large number of people currently eligible to receive community mental health support won't be any more under the NDIS. Just how their needs will be responded to is yet to be considered.

Consumers' right and need to be included in the social and economic fabric of society, on an equal basis with others, must be addressed by the MHCSS and other community support organisations; their need to access appropriate housing, health services and employment opportunities must be front-and-centre of the work of the community sector and much needs to be done to address the multiple systemic disadvantages faced by people with lived experience, given the ongoing discrimination they suffer on a personal and institutional level. Whilst this may be improving in Victoria, people with lived experience today face numerous barriers to being a part of their community as enjoyed by everyone else.

Literature on social inclusion emphasises that alongside other critical human needs, everyone has a need to be connected to community; there is evidence about the direct correlation between the number of a person's community connections and their wellbeing (measured as physical and mental health, longevity, reported happiness, etc.). Mental health services have responded to this by promoting community inclusion for people living with mental health issues. The problem is that this has largely been addressed from the point of the person with the lived experience and not the community s-he is supposed to be included in.

At this stage in the evolution of the mental health sector, the community support sector in particular, has embraced and encouraged the consumer-developed concept of *recovery*. Working within

this paradigm, many new MHCSSs and a few clinical services are supporting the development of new, innovative ways to promote consumer leadership, developing new consumer roles and initiatives, including peer support initiatives and embedding service co-design into their organisations. These are all critically important and without the commitment of services to enable this body of consumer work, little would be achieved. These opportunities, however, are only open to members of the consumer workforce or consumers who meet the criteria for admission into the service. In addition, service culture and attitudes about the capacity of consumers, the limitations imposed by funding criteria and the need to satisfy outcome measurement requirements necessarily result in restrictions being placed on the type and extent of work undertaken.

We need to remember too, that the recovery paradigm is a very recent evolution in mental health service delivery and it would be naïve to believe that our understanding won't continue to evolve. The work undertaken by people with lived experience will play a key role in this evolutionary process and the learning, emanating from the work of peer-led groups will form a critical part of developing approaches to supporting and treating people living with mental health issues.

Consumer activity

VMIAC is the Victorian peak body for people with lived experience of mental or emotional distress. Since its inception in 1982, its small staff group has established, facilitated, met with, promoted, championed and otherwise provided support, to a vast number of different types and configurations of groups of consumers. Some of these have been established within mental health services and

some have existed independently of the funded clinical and community mental health sector. Consumer advisory groups, consumer workforce groups, research, project, education or training, therapeutic, skills-based, diagnosis-based, issues-based or interest-based, self-help, peer support and advocacy groups have all been forming, talking, developing ideas, sometimes failing and sometimes succeeding, for as long as VMIAC has existed.

VMIAC has been only a part of a much larger volume of consumer activity over this time; the collective wisdom of the consumer movement, the disjointed network of consumer activity and consumer communities, existing across the state, has grown out of the vast experience we have amassed in starting, supporting and facilitating a myriad of different types of consumer groups and other consumer-focused activities.

People with lived experience have always expressed their desire and preference to be part of a consumer community; since starting to be listened to, consistent and persistent voices confirmed the value of 'drop-ins,' or the importance of group-based activities, or that the most therapeutic aspect of a hospital admission is the support, solace and companionship by other inpatients. The very few Victorian consumers, who have had the opportunity to be part of a peer-run group or community, tend to become strong advocates for its benefits and the value it provides, in enabling them to create lives of quality. In short, consumers will talk about their need for connection with others who have lived experience in whatever language fits their knowledge and experience of peer support. The fundamental request is common: open up opportunities that feel safe and enable people to find and take on valued roles; provide an

environment that is conducive to healing and recovery and which emphasises the value to people of being able to give to others.

Yet, while the rhetoric of "*consumer choice and control*" is increasingly being heard in mental health services, the fact that there is no service response to this loud, articulate consumer voice demonstrates that a paternalistic attitude of "*we value your opinion but we know, better than you, what you need*" continues to drive service development.

Peer-led consumer groups

Whilst drop-in and similar PDRSS attempts to meet the social needs of persons with lived experience run the risk of further marginalisation, years of consumer work and experience has taught us that peer-led consumer groups can provide enabling, inclusive, recovery-focused environments. We are able to make this differentiation because of a range of reasons, some of which we discuss below. The range and complexity of existing lived experience groups make it difficult to talk about a particular "form" of group; all consumer groups have multiple as well as common purposes, a mutual or peer support element always present, simply because that's part of what happens when groups of people with lived experience meet.

The concept of "*consumer work*" is a broad one in the movement, recognising that all consumer-led activity is underpinned by a motivation to develop new and better approaches to addressing the needs of people with lived experience. Of course, many service providers are aiming to do this as well, but the unique capacity of people with lived experience to know what is helpful and what is not and the unique knowledge we have as individuals, about our own needs and preferences,

means that consumers will always be key drivers of positive change in mental health service delivery – especially now that we can be heard. Approaches to treatment and support that reduce our need to use expensive, debilitating clinical treatments currently offered, will drive innovation more effectively than any other motivation.

In terms of measurable outcomes for consumers, evidence of the value of peer-run groups is limited and mostly emanates from outside Australia. Such activities are barely funded by government and many operate at subsistence level, using volunteer labour with no capacity to evaluate or measure the outcomes they achieve. The evidence that does exist suggests that peer-run groups are effective in many ways, including reducing people's need to access clinical services, improving people's reported quality of life, reducing social isolation and enhancing access to resources to be able to live well in the community. We need to gather evidence from our Victorian experience, including evidence about different "models" of peer-run groups.

In examining and developing research about the efficacy of peer-run groups, it is important to be mindful of the era in which this research has been and will continue to be undertaken; deinstitutionalisation is still a recent occurrence; in numerous areas of their lives, people with lived experience continue to be discriminated against and paternalism about their capabilities continues to pervade services. Consumer work, including peer support work, promotes a greater sense of autonomy, control of our own destiny and confidence in our abilities. But this evolution takes time and, in the meantime, we must realise that we are frequently working with a profoundly disenfranchised, misunderstood and damaged group of people.

Based on evidence and our experiences, VMIAC's view is that inclusive, unstructured, independent, peer-run consumer groups, such as that provided by the Maine Connection, are the missing link in a complete public mental health services system in Victoria. A three-pronged structure - in-patient and community clinical services, community support services and independent mutual support and self-help organisations - already exists (the latter, being a small component only, receiving a very small allocation of the overall amount spent on mental health services). Providing broad access to inclusive peer-run groups would ensure a form of support accessible to anyone. Not all people with lived experience want or need to access mental health-specific support, but those who feel the need for a peer-support group should be able to access one as a multitude of other special interest groups do. Some people living with mental health issues would only need access to a peer-led group to support them in maintaining good mental health, while other people may access two or more alternative service types.

In VMIAC's preferred model, peer-led groups are developed according to principles of group ownership and individual choice; decisions about the group are made by the group and decision-making is often consensual, reached after inclusive discussion. Most decisions don't need consensus; if only eight people want to organise a camp or only five want to access Pilates, only those interested will work on this.

The Maine Connection's lack of a service 'model' means that no groups would develop in the same way, each group responding to its unique membership and culture and its members' expressed wishes. Inclusive, unstructured peer-run groups can deliver a multitude of functions and the remainder of this chapter will explore some of those.

An alternative, more consumer-friendly way to promote social inclusion

In many ways, independent peer-run groups are better placed than MHCSSs to meet people's need for community connection. "*Inclusiveness*" is a major strength of an independent approach to peer support, whereby anyone identifying with the need to be part of a supportive group is welcome to attend, thus adding strength through diversity. Funded MHCSSs, in contrast, can only provide a service to people who meet their narrow criteria, skewing their membership, as only people with specific, defined characteristics or needs can be included.

We have learned that peer-run groups generate their own level of interaction with communities and, hence, safe and empowering opportunities for broader community inclusion beyond the group. For example, a local provider may ask to consult the group about the development of a community mental health plan, or a Local Council may seek a representative to sit on their community access committee. Group members might organise a Mental Health Week event or partner with another organisation to start a choir or other activity. A few group members might find a shared interest resulting in their participation in joint community activities.

Opportunities for education, training and information sharing to group members

We see a developing need for people with lived experience to have a point of contact, enabling them to access information about the changing service system, to gain training and support to navigate the new NDIS and advocate for their interests or exercise their rights under the Mental Health Act. VMIAC's experience is that many organisations wish to deliver information to people living with mental health issues and

consumer groups are an efficient and effective way to communicate directly with consumers.

As well, members share information with each other in peer-run groups; a subtle but important difference exists between a support worker, telling a client about a doctor open for new referrals and the person learning about that doctor from a friend, at their local peer support group!

Flexibility

People with lived experience use peer groups in different ways, according to their own needs and preferences; some people become committed members for long periods of time; others stay for months or years, before they move on to take up other life opportunities; yet others come along on a casual basis or, they "revisit" the group from time to time. Not being bound by funding criteria, independent peer-run groups allow people to use the group flexibly, according to individual choice, changing circumstances and needs. People can participate, to the extent they choose, at any stage of their engagement, without needing to provide evidence of eligibility or having to commit to a specific program or period of involvement; some people need this level of flexibility to enable them to maintain the connection.

For many years, VMIAC has heard the call for access to peer communities, many people talking about the value of having this "*touchstone*" relationship with a peer group to support them in maintaining connections within the broader community. Even when they develop strong community connections outside the consumer community, many say that their capacity to do so is enhanced by being in groups where their lived experience is accepted and they can talk openly about their experiences.

Peer groupwork

In a broad sense, the focus of this chapter has been on unstructured, inclusive, independent, peer-run groups, where at least one of the core purposes is to provide peer support and community to people with lived experience of mental health issues or emotional distress. In the broad family of peer-run groups, classifications can be made that could be useful in shedding light on the complexity of the need for peer group work. One way to describe peer groups, for example, is to differentiate between those that are established within a service provider organisation and those that are independent from such organisations.

A second point of differentiation is that between groups whose purpose is to provide mutual support and self-help, information or education opportunities to a well-defined subgroup of people with lived experience and groups with more inclusive membership criteria. In the first category, groups such as those facilitated by PANDA (Post and Antenatal Depression Association) and Compassionate Friends, Hearing Voices Network groups and numerous depression and bipolar support groups provide peer support, information, advocacy and education opportunities to members; others, such as GROW groups and the Maine Connection (featured elsewhere in this book) have very open membership criteria.

A third axis of differentiation is those groups that have a structure or framework within which activities take place and members interact and those that are specifically non-structured. An example of this is the difference between the GROW groups, adopting a form of 12-step program to support their members towards recovery, and

the Maine Connection, which has consciously chosen to provide an unstructured space.

All these types of groups provide valuable functions and directly respond to a need expressed, by a group of people with lived experience; importantly, whether paid or not, everyone is a peer worker in a peer-run group.

Compared to other developed economies, governments across Australia have been conservative about providing funding to support the development of the consumer workforce, including the development of independent, peer-run consumer organisations; however, future developments in our understanding of and responses to mental health issues will arise from the work done by people with lived experience.

Locally and around the world, consumers have been developing concepts like *recovery* and increasing understanding of trauma-informed care; exciting and innovative approaches to working with people who hear voices and the benefits of alternative therapies which are becoming mainstream are being driven by the work of consumers, either independently or in collaboration with other providers. Only with government investing in this work, including in the valuable work occurring in peer-run groups, will future, more rights- and recovery-focused

services and treatments emerge. As healthcare costs continue to rise and demand for mental health services continues to expand, this must be seen as a win-win approach.

We want a future, where people with lived experience of mental health issues, have the same capacity to access the resources needed to maintain a quality life, and to be included in social and economic activities on an equal basis with others. As long as people with lived experience are discriminated against in a range of ways we need to ensure that they can still enjoy community connection, meaningful activities and a quality of life within their own communities of choice before reaching out, in friendship and respect, to the very society that has discriminated against them.

How GROW Works

The Grow Group

How GROW Works

This chapter provides a short explanation of the mutual support groups provided by Grow and the associated activities that support Groups and Group members in their recovery to good mental health. This is then followed by an overview of Grow's history, how the Grow Program was developed and how it has been sustained and continually developed over the past 55+ years. The final section offers a personal story of recovery using the Grow approach. We are very grateful to the Grow member who was willing to provide her very personal story of recovery and changed her name to Margo West to ensure privacy. This story of recovery shows what can happen when theory becomes practice, as Margo's immersion in Grow enabled her to overcome chronic depression and return to study and paid employment.

What Grow offers

Grow establishes and develops peer support groups based on the principles of mutual help, or as we prefer to say in Grow, *self-activation through mutual help*. The groups are suitable for adults seeking recovery from mental illness, as well as for those seeking prevention. In addition to mutual support groups, a host of other activities are available, including education and training, community building and social activities, all underpinning the work of the group and recovery from mental illness. No cost or eligibility criteria or formal intake processes for attendance at a Grow Group exist; however, those that decide to become members must acknowledge the challenges and disorder they are experiencing in their life and make a commitment to use the Grow Program to support their recovery. Groups are run by the members, using their experience and support to overcome life's challenges and recover their mental health. The approximately 200 groups in Australia are established locally and run in community centres, local libraries etc.

Early Beginnings and a 12-Step Model of Recovery

Grow's very first meeting took place on the 26th April 1957 at Hurstville, Sydney. At that time many individuals, with a mental illness, were being discharged from hospital into the community without community supports. As a result, a number drifted into Alcoholics Anonymous (A.A.) where they found acceptance, support and assistance for improving their mental health. As their problems were somewhat different, they decided to form their own group, which would enable them to work more systematically on the particular problems related to mental illness.

With the help of some caring A.A. friends, the first meeting was organised with thirteen individuals present; the name *Recovery* was chosen for

the group in order to emphasise the goal and the solution, rather than the problem (Keogh 1979:11) and it was not until the early 70's that the name was changed to *Grow*. At that first meeting in 1957, there was a decision to:

• Use to the utmost their own personal resources;

• Help themselves and help one another;

• Try to identify, write down and keep the beliefs, values, attitudes and problem-solving techniques that assisted in their recovery.

Consequently, a separate type of meeting was held where *problems* were not discussed, rather the focus being on what was helping recovery; this type of meeting became known as the *Leadership Meeting*, at which members wrote down what was agreed as helping their growth and recovery. All written notes were kept, marking the beginning of Grow's written Program and modus operandi. One example should suffice: "*Settle for disorder in lesser things for the sake of order in greater things; and therefore be content to be discontent in many things.*" (Blue Book 2012:15).

To this day, Leadership Meetings continue to be held for the same purpose; by staying faithful to the initial resolve, to preserve what had worked and what had been learned. Consequently, the organisation now has a vast amount of written Program material and other literature which includes:

1. A well documented *12 Step Program of Recovery and Personal Growth*;

2. A written structure for Group Meetings known as *the Group Method*;

3. A wealth of written material on how to build *a Caring and Sharing Community*;

4. A *Legal and Organisational structure* that enables Grow member involvement at all levels, including organising and running support groups and management at both the local and National level.

These four features are described as Grow's essential features and while they are well established, all are open to revision and change, particularly the program. In recent years, Grow's Program of Recovery and Personal Growth contained in and affectionately known as the "*Blue Book*", has been revised by Grow leaders, as has the Group Method. The Board has also revised the Organisational structure in recent years.

For those who make a decision to use Grow, as a means of recovery or personal growth, the four essential features work together, to maximise their recovery and well-being. They are identified and discussed separately here, but they are intricately intertwined.

The first essential feature - the Grow Program of Recovery and Personal Growth

The 12 Steps of the Grow Program are written down and expanded upon in the *Blue Book* – a pocket-size book which the majority of Grow members will own and carry with them, most of the time, particularly during their early days in the group.

In addition to the Blue Book, the program includes several Books of Readings on Mental Health published by Grow. This literature is arranged in 12-Step order, comprising Program articles, suitable in size for reading and discussion at

weekly group meetings. This combined program literature is *the guiding philosophy* for all Grow support groups and residential programs.

The foundation stone of the Program is outlined, in its first Principle of Personal, acknowledging a firm belief in the inestimable value of *all* human beings, whatever their past or present physical, mental, social or spiritual condition (Blue Book 2012:12). Accepting this belief, about oneself and others, and treating people in accordance with this belief is a challenge to many in to group, but essential for personal growth and recovery through Grow. The Program provides a holistic life philosophy and is primarily about personal change and personal growth (Blue Book 2012:20), brought about by what has been defined as "*The Three Basic Changes (for the development of my New Self):*

1. Change of thinking and talk

2. *Change of behaviour*

3. *Change of relationships.*"

Learning, understanding and adopting the Grow program, will assist individuals to work on these three basic changes and enable them to progress towards the goal of the Grow Program: mental health or maturity (Blue Book 2012:11). The 12-Steps outline a way of constructive change and growth, though not necessarily in consecutive order; members assist one another at group meetings, with suggestions for using suitable "parts" of the program in response to a problem shared. These parts of the program, or "*wisdoms*" as they are sometimes called, will always relate to one or more of the 12-Steps and of the three basic changes. As one researcher into Grow explains, "*The program most frequently used, from the Blue Book,*

could be described as a layperson's cognitive behavioural-therapy (CBT)" (Finn et al 2004:4).

As members develop their knowledge and understanding of the program and, more importantly, *their capacity to apply this in their life*, recovery commences and continues and they become able to share this knowledge and experience with others in the group, the person being helped becoming helper as well. However, if the program becomes just another theory or philosophy to be learned and understood (as sometimes happens), it becomes a purely intellectual exercise and personal growth becomes impossible. Application of the Program is where personal change occurs and is, therefore, paramount for recovery.

The journey from Step 1 to Step 12 requires a great deal of patience and perseverance and therefore takes time; there is no "*quick fix*". Philosophically, Grow believes that recovery to good mental health is not a journey to be taken alone, requiring the help, care and support of others and this is why mutual help, friendship and community are so important in Grow.

The organisation is fortunate that its foundation members had the foresight to write down the Program and ensure that this process remained ongoing. While the written word can be quite powerful, experience in Grow has shown that, it is the individuals who know and use the Program and carry it in their minds, hearts and relationships that bring it alive, both for themselves and for others. They are the key leaders and stewards of this program, having taken the time to incorporate it into their own life; many remain in Grow, no longer for their own needs, but to pass on their experience and knowledge to others.

Grow would not work without these volunteer Leaders, for they have the capacity to inspire, encourage and give hope to other Grow members and act as role models for newer members, exemplifying the Twelfth Step of the Program: "*We carried Grow's hopeful and healing message to others in need*" (Blue Book 2012:10).

The second essential feature - The Group Method

While problem solving is an important part of any Grow meeting, groups are, first and foremost, a friendly encounter of persons. It is in attending group that a person will, initially, come into contact with a microcosm of Grow's Caring and Sharing Community.

Grow groups do not have facilitators. Each group has a volunteer Organiser, elected from within its own membership. All Organisers are provided with extensive training, to enable them to fulfil their role. There is additional support available, to Organisers and to the group itself, from fieldworkers (staff). Group organisers also provide support, to new or struggling groups and support each other, in their leadership role, within geographical regions.

The structured Group Method, written down in detail, is distributed to each person present at every meeting and provides the framework for the meeting. Leading a meeting, in accordance with the Group Method, is available to members of the group who have made a commitment to group membership and who have attended group for a minimum of 3 months. The Organiser chooses who leads each meeting and will assist the person in this endeavour, if necessary. Other group tasks are also shared amongst group members and all are encouraged to assume responsibility for the

group, which contributes to the recovery process and can provide meaning and purpose.

A well-functioning group will activate the use of the Program, during the meeting, by ensuring the Group Method is followed with fidelity and flexibility, thus safeguarding what Grow would call *the ingredients of a good meeting*:

- An experienced leader shares a Personal Story of recovery, showing how they have managed to change and grow using the Program (Margo West's is an excellent example). This activity provides hope to members.

- Problem solving is done effectively and each person sharing a problem is given a small part of the Program and is allocated a practical task, by group members, to work on during the coming week. This process helps critical learning and skills development.

- Members are given time to report on progress achieved in using the Program/practical task during the previous week. Progress is celebrated and setbacks examined.

- Education in mental health takes place during the course of the meeting, through reading and discussion of Program Commentary.

Practical tasks are arranged at group meetings and worked out in accordance with the individual's capacity to do a particular task, its degree of difficulty increasing as the member's confidence and personal resources increase. Tasks provide the means for a "*change of behaviour*" and they may well include a means to change the way we relate to others. Practical tasks will be in line with current Program usage that offers a "*change of thinking*" and members support one another with set tasks, either by telephone or in person.

When sufficient progress has been made and the journey to recovery is well on the way, members are encouraged by the group to take their responsible and caring place in the wider community (Step 10 of the Program). Not surprisingly, this is different for each person; it may be that an individual is encouraged to return to work (at home, voluntary or paid) or take on some study, or join a club, in order to make some social connections outside Grow. Stepping outside one's "*comfort zone*" requires encouragement, support and risk-taking. The group will provide such support and encouragement as members gently challenge one another, at appropriate times, to step out into the community beyond Grow.

The Third Essential Feature - The Caring and Sharing Community

Grow believes that a nurturing, caring environment provides a safe haven, where individuals can develop the courage to share their innermost thoughts and feelings and, consequently, be open to the possibility of change. While the Caring and Sharing Community starts at the Grow group, it expands to every activity in the Organisation; known as *the wider community of Gro. The* many activities provided through group membership are available, including:

- Training days,

- Program study sessions,

- Residential community building weekends,

- Residential training and leadership weekends, and

- Social activities at both a local, regional and state level.

Such activities, as well as providing education in mental health, provide an opportunity to practise listening, communication and social skills, as well as having fun! People have the opportunity to participate in a host of teams, providing an avenue for the practise of existing talents and/or the development of new skills.

Important for community building is companionship, friendship and leadership; and whilst growth into friendship and community is gradual, companionship may be experienced very early on in Grow by attending group, participating in telephone calls between meetings and attending regular social activities. Establishing a network-of-friends for living takes much longer, and this is fostered and encouraged at all levels of involvement.

The caring qualities of the Community, will always reflect the qualities of the individuals, who make up the community; thus, all in Grow are invited to develop the following personal (and therefore community) qualities and cultivate them in their relationships with others. These personal and community attributes are identified as, though not limited to, the following:

- Dependability and readiness;

- Helpfulness and thoroughness;

- Appreciation and warmth;

- Compassion and tenderness.
  (Blue Book 2007:34)

Grow acknowledges that building such a community is idealistic, but these ideals provide the Grow Community with direction: "*Ideals are like stars: you will not succeed in touching them with your hands, but like the seafaring man on the ocean desert of waters, you choose them as your guides, and following them, you reach*

your destiny." (Schurz, C. 1911) Many individuals returning to group, beyond the first meeting, have stated that this warm acceptance of the Caring and Sharing Community and the sense of belonging it creates, was the key factor in their decision to return. For some, particularly those with no family connections, the Grow community often becomes a form of "*extended family*" or a "*place to belong*".

The Fourth Essential Feature – Legal & Organisational Structure

The Grow organisational structure is designed to preserve and promote the life of the community, while at the same time effectively managing the affairs of the organisation. It promotes community building and requires a personal, rather than an impersonal or detached, approach to management. This community building structure is also designed to enable maximum participation in Grow, ensuring it remains "consumer" driven. Involvement by Grow members, in organisational leadership roles, requires them to take on organisational responsibility and participate in relevant training, at each level of involvement. This provides an additional avenue, for further developing skills, knowledge, confidence and leadership.

The structure starts with the election of an Organiser at group level. Organisers, by virtue of their role, become members of the local regional Management Team, as well as becoming eligible for election to state-based, Branch Program Teams. From there, they may be elected to a state-based Branch Management Team, the National Program Team or potentially become a member of the national Board of Grow.

It is also worth noting that Grow employs fieldworkers, who take responsibility for quality control and support of around 7 – 10 groups in a given region. Most fieldworkers commenced in Grow as ordinary group members, were elected to the role of Organiser and became more deeply involved in the organisational structure. As paid staff/fieldworkers, they are able to control quality of around 7 – 10 groups together with Organisers and Recorders. Fieldworkers are provided with ongoing in-house and external training.

Introduction to Margo's story

Margo's story illustrates how immersion in Grow's essential features, particularly the first three, has enabled her recovery. Her venture into the organisational structure, though not helpful to her in the usual manner, was an experience she learned from, albeit in hindsight. As the years pass, Margo becomes very resilient, so much so that even a divorce does not cause the depression to return. Whilst not stated by her, discussions reveal she has been an "on and off" Grow member for seven years and, at the time of writing, is a member, having had several "breaks" from Grow during this time, each lasting more than 6 months.

Given the several "breaks" she had, the actual time she spent in Grow is approximately 5 years. This time factor is important to note when reading her story, as the changes she describes did not happen quickly; they are the result of Margo's willingness to patiently persevere with learning, understanding and adopting the program and systematically developing and using her own personal resources – all with the help of a caring Community.

Margo West's Personal Story of Recovery

My story is one of overcoming chronic major depression. At age 31, I had become a shadow of myself. Once a confident, intelligent young

woman with her whole life ahead of her - a career mapped out, a relationship with a kind, gentle man and plans to raise a family - now I was extremely vulnerable. I had stopped going to work a few months back and on many days, I did not leave the house. On particularly bad days, I stayed in bed, generally getting up and dragging myself to the shower 15 minutes before my husband was due to arrive home. I had also lost my confidence in driving, so a family member took me to my first Grow meeting.

The thing that stood out for me that first night and made me feel close to the people in that room was that they spoke about having the same (what I thought were crazy) thoughts as I did! Somehow hearing them spoken out loud made me feel less crazy for having them. Also, I was in awe of the Group Organiser. He had so much energy, passion and zest for life. I admired it AND wanted some for myself. He reflected back to me a way of being that I had once had and had lost.

Eventually I learned about Program Study on Thursdays. This made a big difference to me. I embraced that one hour a week to delve deeper into the Grow Program. I thought that it contained much practical common sense and wisdom and I wanted to understand it in theory so that I could apply it in my life. I started to change slowly, through a combination of weekly Grow group, Program Study, 12-Step calls and social events. I realised that for the first time in my life I was taking my mental health seriously.

About 2 to 3 months into attending Grow, I admitted myself to the local Hospital's Mental Health Unit. I had been trying to medicate my pain with hard liquor and marijuana and was going downhill. I told my housemate I wanted to die because I knew from past experience that if I told my husband, he wouldn't take it seriously

enough, and this time I felt something had to be done. I probably scared her (and him for that matter) by saying concrete things like "I'm going to step in front of that bus now". They physically restrained me, and shortly after, when I asked to go to hospital, they took me. To me, that was my rock bottom.

I stayed in hospital overnight, and had my medication changed from anti-depressives to anti-anxiety meds. All alone … for what seemed interminable hours … in a locked room, I had the realisation that no matter who's fault it was that I was ill (and honestly at that time, I probably blamed my parents), it was up to **me** to get the help that I needed in order to heal. That was powerful and I stopped waiting for someone else, such as my husband, to "save" me. This insight relates to a section in the Blue Book (2007:25) that talks about **personal responsibility**. I left the hospital the next morning with a shred of hope once again.

Thankfully, I had Grow to return to. Though it may sound like going into hospital was a sign that I was getting worse, it was just another part of my journey towards getting better. It marked the point where I had reached a level of **acceptance** about my depression and anxiety. I had shown my family that I needed treatment and that I wasn't OK and this **truth** set me free. It was the beginning of finally getting well. There is a section in the Blue Book (p.26) on Truth that reads: **"Mental health … comes from thinking, speaking and living truly"**. By owning up to the fact of my life - that I was depressed - rather than buying into the story of my life that I had imagined for myself in which nothing went wrong, I was on my way towards better mental health.

Over time, the friendship and support of a caring community helped me too. Having a place to go

and people to be with who accepted me at my weakest point was life-affirming and gave me infinite **personal value**. Also, I started to have **fun** in social situations again and it felt good! So I kept going to as many Grow functions as I could in addition to the weekly meetings.

Less than a year after starting at Grow, the group I was attending started the search for a new Organiser. Having been a high achiever through school, I decided this could be my opportunity to shine. Shortly after, a job vacancy opened up at the local branch office. I had done admin. work before and though I loathed the thought of sitting behind a desk again, my love affair with Grow drove me to take it. It wasn't long before my well-being took a turn for the worse. Not surprisingly, I eventually had to step down from both the Organiser role and the admin. position. It turned out to be another step in my journey to figuring out what my true talents and passions are.

At first, the parts of the program that helped me were the one-liners, simply because I could remember them. Some of my favourites were:

- Don't be an emotional reaction, be a person.

- **Live one day at a time.** I expanded this to: **live one hour, one moment, if you have to**.

- **Don't be shy about being shy.** I was painfully shy in those early days and beat myself up about it.

- **Confidence is not a feeling but an attitude of mind.** This one intrigued me because I had always believed it was a feeling.

- Have the courage to make mistakes.

- **Growth is painful, but permanently rewarding.** This kept me going when it all felt too hard.

I was given Personal Value (Blue Book 2012:12) to look at early on and I remember getting angry when reading it. I thought it was quite possibly the stupidest thing I'd ever heard and, even if it applied to other people, it didn't apply to me. I said it to myself over and over again for a long time. Now if someone were to ask me what part of the Grow Program has had the most positive impact on my life, I would have to say Personal Value.

Also powerful to me were the parts of the program that we recited at every meeting; because of this repetition, they stuck in my head:

> The Grow Aspiration: **"May the spirit of friendship make us free and whole persons, and gentle builders of a free and whole community** (Blue Book 2004:79). This flooded me with warm feelings towards the group.

> A section in the Affirmation of Good that reads: **"we freely forgive from our hearts those who have wronged or failed us - including our own selves"** (Blue Book 2004:78). I was definitely the hardest person to forgive in my own life.

In 2008, my marriage broke down and I had to draw on all my personal resources and strength to get me through. Whereas something like that would have flattened me before, I didn't lose a single day in bed over it. I settled for disorder big time (Blue Book, 2004:9). I felt the pain and the sadness of being left by my beloved partner of 8 years - the man I had shared most of my life's ups and downs with - and I didn't become depressed by it. The feelings came and went like bad weather (Blue Book 2012:21).

I didn't panic or overdramatise the situation because it was happening to me (Blue Book

2007:40). Over time, I began to see my own contribution to the disintegration of our relationship and I started the work of forgiving myself. I stopped blaming my partner and feeling like the victim in my own life. I found strength and empowerment where once I had found weakness and dependence upon another.

The present is one I never imagined because I thought that I would be married to my ex for the rest of my life. It is so much **better** than I imagined! I have been completely depression-free for 1 year and counting. I work at a job I love, study for a career that I believe will challenge and inspire me, and hope to have children of my own one day.

Now the future seems like a great and undiscovered mystery. I don't fear it like I used to. I don't want my life to stop like I did when I was in the thick of my depression. I am curious and hopeful and trusting. Most days, I've got my energy, passion and zest for life back. And on the days that I don't, I find contentment in the quiet and in the knowledge that I have come through something very difficult and can still smile.

Endnotes

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The Maine Connection –
an inclusive, volunteer,
consumer community

David

*(For more about the Maine Connection or to organise a visit,
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The Maine Connection — an inclusive, volunteer, consumer community

It is often convenient to ignore the reality that communities exclude as well as include; religions, clubs, associations, unions, workplaces and political parties are broadly inclusive, provided that potential members share basic philosophical beliefs.

The **Maine Connection** is inclusive of people, ideas, therapies and beliefs. It will welcome any community member who is supportive of its aims and maintains that all people are best capable of mapping their own path to recovery and that the inevitable detours are sometimes helpful learning experiences. It seeks to support people in their recovery, in the ways that they choose. That foundational statement reflects our desire to be inclusive and defines our boundaries; we don't believe that '*one size fits all*,' or that '*recovery*' is an *event* rather calling it a process or a journey. While people with a '*program agenda*' are not excluded, we have found that they look elsewhere when they are met with members' preference to maintain the diversity of views the group has established.

We began to meet on a regular basis in May, 2004; by October 2007, we had fleshed out our core principles and aims; our core **principles** are brief and simple; each of us:

- has unique knowledge of our own lived experience;

- makes meaning of our own experience;

- is the expert in our own experience;

- is the expert on our own mental and emotional status;

- has expert knowledge of 'what works' for us;

- is the expert on establishing our own needs;

- is equally privileged in being heard.

Our **aims** reflect our philosophy and core principles:

- To develop and maintain an inclusive, supportive community of people who have experienced mental health problems, emotional distress or social isolation in the Mt Alexander Shire;

- To provide supportive advocacy for those who request it;

- To support people to achieve their personal goals in physical and mental health, in developing and maintaining financial independence and in participating fully in the local communities of their choice;

- To provide members with opportunities for paid work;

- To improve services for people in the Mt Alexander Shire;

- To improve public mental health services in the Loddon Southern Mallee Region and across Victoria;

- To provide an independent source of advice to community groups who wish to provide mutual support, advocacy and self-help to members of their own communities.

From the onset, we wanted to be *inclusive*; one of the main reasons members felt a need for the Maine Connection, was the difficulties experienced by some people in accessing services or being discharged from a service without consultation. People had sometimes been excluded from learning activities because they had the '*wrong*' diagnosis. The first real decision members took was that we would be inclusive - *'a support and advocacy group for people experiencing mental health problems, emotional issues or social isolation'*. If somebody wants to come, they are welcome. We have no criteria for attendance and we don't ask for diagnoses or referral forms. People are free to disclose as much, or as little, personal information as they choose. Different groups of people, diagnosed with a mental illness, will have different reasons for wanting to start their own community-based group. Perhaps the single essential reason is that a number of people express a need for it. If that need isn't obvious, then perhaps discussions around some of the points in this chapter will determine whether the need exists in your area.

In Mount Alexander Shire, based in the Central Victorian Regional City of Castlemaine, the need was first expressed as people wanting a space of their own, a place free of clinical and community workers, where discussions would not be censored, assessments not made, criteria of admission not even considered let alone enforced; welcoming of the community as, we believed the community ought be welcoming of us. This is one of the reasons why we think of ourselves as a *consumer community* rather than a consumer *group*. So, given that our motives and philosophies (whatever they might be), have led us to try to start up a *group*, where do we go from here?

Getting started

Establish that there is a *need* for a consumer-run, consumer-developed and consumer-controlled group. Some of the reasons given in this chapter might be useful starting points for a discussion.

Establish that there is a *commitment* by at least a couple of people who will turn up to meetings for 6 months, whether or not anybody else does.

Establish the *time and place* for the next meeting of the group, on a day suitable for most people, at a time that allows for school pickups and other essential activities.

Location

Maybe the most important question of all! Meetings ought to start immediately, otherwise you lose the momentum of the first flush of enthusiasm. Unless you've already got a venue, you might have to meet at someone's home. This is rarely a good option, but sometimes necessary. We did it for the first few weeks. The first meetings need to allow plenty of time for ideas about possible venues. Church halls, sports clubs, community halls, Community House, Shire facilities are some of the ideas we threw around. Ask people who have time to see what they can find out and bring to your next meeting; two of our members found a terrific hall, with kitchen facilities and secure space, owned by the Office of Housing and managed by the Shire. We've used this space ever since (rent-free, because we've always attracted some local residents as members). Our other space was *The Shed*, a disused commercial chook-shed, just out of town and owned by one member.

How often?

How often we want to meet depends on a lot of things: how often do people *want* to meet; how often will someone *commit* to attending? We decided on once a week, from 10.30 till 2.30, with options to scale up or down, depending on how we went. From August 2005 until March 2012, we met twice a week, which allowed some who couldn't make it on Tuesday to come on Friday afternoons (1-4). Since then, we have reverted to one day a week by consensus. This summer, for a change, at the suggestion of one of our newest members, we'll have a few evening meetings at the local BBQ area at the Castlemaine Botanical Gardens, also giving workers and students a chance to attend. If that works, it will probably become an annual fixture throughout the daylight-saving period.

Funding

Start thinking about finances; knowing that there will be a cuppa and biscuits encourages people to attend the group. Knowing there's a charge, however small, will keep some people away, some of the time - and often, they will be those who get the most out of the group. For donations, try the local Shire, service groups like Rotary and Apex, churches, mental health clinical service, your MHCSS (formerly PDRSS), your supermarket or from anywhere in the local community. Our MHCSS, St Luke's, gave us a 'seeding grant' of $500, which gave us a terrific start. Try to access 'undirected' funding, which can be used however members decide. We've used ours to provide morning/afternoon tea and a weekly meal for whoever turns up. We have been incredibly fortunate that a local philanthropic group, the *Angel Fund*, provided us from the beginning, with finances to offer a free meal and morning and afternoon tea.

Grants

Your local Department of Health office provides a small Health Self-Help and Disability Self-Help Funding Program, for *'meeting costs'* each year which will provide for renting a space, utilities, paper (programs, newsletters etc.), archiving requirements (folders, filing etc.). We've applied for several grants, from a variety of sources; the YMCA offered an opportunity to pilot Mental Health Camps; they had grants provide 2 camps and we received a grant ourselves for a third one, through BankMecu with whom we have an account. The Shire offered funds to run a Pilates program for locals who could otherwise not afford them.

Records

Financial records are essential for group harmony and public 'accountability. Concerns about spending are easier to deal with if receipts for monies spent can be shown; a simple spreadsheet is all that's needed, plus a safe place for storing documentation.

Attendance records provide a useful 'history' of the group, also recording visitors; first names are sufficient. We don't keep personal files on anyone and believe this is critical, to ensure people feel free to express themselves, not being judged or assessed by others. They also provide data[52] which can be useful in applying for grants or other funding.

Membership

Be inclusive, which also means welcoming visitors. We've had consultations (more than 30, most of them 'paid' in some way), visits from members' case managers or key workers, as well as Council staff, who have given us opportunities to become involved in community activities. We also decided to charge no membership fee, so that nobody would be excluded because of poverty.

Relationships

Let the community know you exist; our first and now oldest relationship has been with *VMIAC*, Victoria's peak consumer body, who have been readily available for practical and moral support. *Our Consumer Place* was founded in 2007 and provides another valuable avenue of information, support and expertise. The *YMCA* supported us to have an annual group camp for three years and we've run 2 of our own since then, camps becoming a biennial event, the keenest camper among us collecting small amounts over 2 years, till we've all put in $250. That was enough to have camps, at Warrnambool and Picnic Point, in shared cabins, leaving enough to start the next camp fund. The local *Neighbourhood or Community House* may provide a temporary venue and activities as well as lots of practical, local advice. Community Mental Health and your local *MHCSS* (if you have them) can let people know when and where you meet. *Local Shire (or Council)* contacts are useful; a large amount of local knowledge is held by Council workers. The *Castlemaine Peace Choir* became a focal point for many members to engage with the wider community. It's a Neighbourhood House program, partnering with the Maine Connection, St Luke's and Windarring (a local disability service).

Decision Making

The disempowerment many consumers feel is part of what creates the need for this kind of group. Decisions don't have to be made till there is agreement; taking the time to get people on board - or to realise that they aren't on board - is essential. Things can always be revisited. Part of becoming re-empowered is learning to say *no*. In late-2004, some of us wanted to circulate a brochure advertising the Maine Connection in the community; several people objected and there was a clearly-stated fear that we might be '*taken over*' by outside people. The brochure was finally put out less than 12 months later, but everyone was happy with it by then, confident that the group was strong enough to survive.

Activities

These depend on decisions, the group makes, as well as opportunities that open up. *Drop-in*, now a dirty word for most support services, is an essential feature of many people coming to terms with what's happened and is happening to them. Unstructured social time is often an opportunity for people to gather their breath, reflect on their present and past circumstances and work out, in their own time, where, when and how they want to get on with the rest of their lives.

"…it's just a bunch of locals getting together to help each other out where we can."

Belonging to a community is one of the primary reasons people are a part of any group. Many consumers feel isolated from their original communities (family, church, clubs, workmates, friendship networks) because of the circumstances surrounding their illness and their own or others' stigma. Feeling 'at home'

in the group is often a first step to dipping a toe back into the wider community. Re-entry to the wider community is easier when you know people, who are already part of the community, through their own social networks. *Inclusiveness*, inviting people to visit the group, is often a way of breaking down the seeming *exclusiveness* of the wider community. Communities eat together; it's part of the building and maintaining of community. Our first donations were used to provide morning tea for those who came; we've always been able to offer all-comers a cuppa and a nibble. The thought of a cuppa can be the deciding factor in whether someone leaves home on a miserable day. A community meal, as often as the group can provide one, helps people bond. We've been very fortunate that our major benefactor, the Angel Fund, believe in the importance of communal eating even more strongly than we do!

Community is important to every one of us. Social research has shown that people who have strong and multiple community connections enjoy better health, are happier and live longer.

Mental health services often exclude people. Public mental health services are funded to provide a service to "*people diagnosed with a serious mental illness or disorder*;" they are also expected to discharge people when they need to accommodate new clients, or believe the clients no longer need the service. Unfortunately, decisions about who gets access to a service and who doesn't are ultimately made by the service, often with little or no consideration of the person's own view of their needs.

Relationships with friends and family can be lost along the journey through mental illness and living in poverty can mean that affordable chances to socialise are hard to find. People can lose the

confidence to socialise in the broader community, especially if they have felt the stigma of having a mental illness. Many consumers say that they would like, or need, to belong to a community of other consumers - people who won't judge or who can understand where a person's been and what they might have been through. This isn't unusual: women, lawyers, teachers, veterans, hearing-impaired people, fishermen, and so on … all people enjoy the company of others who speak the same language, who we feel can understand us.

The Maine Connection is proud that we are a 'community' rather than a 'service'; we've formed strong views about social inclusion, which seems to have two related but different aspects; the first aspect is about human rights as described in the Victorian Charter of Human Rights - including access to housing, employment opportunities, equality before the law, freedom of expression etc. The second characteristic is about the needs most of us have, as social beings, to enjoy the company of others. We support human rights through advocacy, education and being eager participants in research projects, by a variety of organisations, including the Department of Health. We provide our needs, as social beings, through our own consumer community itself as well as by inviting community members to join us and by being open to opportunities such as table tennis, choirs and camping programs that come up from time to time.

Why do mental health services actively work to break down or discourage consumer communities? Although most services have a goal of social inclusion, as a strong policy statement, they design their programs around getting people involved in the broader community rather than supporting a community of consumers. It is not the only community to which members belong, but it is a strong place where people can feel

included and safe, get their bearings and make decisions about where they want to go.

Clinical and Psychiatric Support Services, while often necessary, exercise a large degree of control over us, through their ability to subject us to involuntary treatment and to deny us treatment or support. Because the Maine Connection is socially inclusive, our community is stronger; we have developed close friendships with each other, which carry over into time spent together outside the gatherings of the group. In the time we've been together, groups of members have become part of the local table tennis competition, gone camping regularly, been foundation members of the Castlemaine Peace Choir, become involved in buying and selling at local garage sales and organised, or helped, at the three Mental Health Week Concerts we've put on with the help and support of local musicians and our local MHCSS.

Being inclusive has considerably expanded people's opportunities to re-engage with the broader community and the consumer community we've established has helped people develop the confidence and self-esteem that are critical to successful community engagement.

How does the Maine Connection work?

We currently meet on Tuesdays from 10:30 till 2:30, at a community hall in Castlemaine. There is no charge or membership fee; tea and coffee are provided and we have a light lunch, nothing very fancy. Maybe once a month we have an 'agenda' – consumers from another town visiting, a consultation with a government or academic department, workers from the Shire or a health service, a birthday or Christmas/New Year party. For most of the time, it's just the people who turn up on the day and we talk about our lives, our

circumstances, our hobbies, TV, movies, sport and current events. If anything interesting in mental health has happened, it will usually get a run; if someone's struggling we'll talk about that – if they want. Mental health probably gets less attention than physical health does, which is unsurprising as we all know they're inseparable, even if that seems to escape psychiatry.

Consumers know it is essential to talk about their experiences of illness, trauma, treatment and side-effects, as one way of learning to deal with their circumstances. Some topics, like self-harm or suicide, need to be treated sensitively, but making certain topics taboo, as some mental health services do, doesn't help people address their feelings and fears. It is difficult to quantify the importance of the ability to talk freely, to imagine and suggest, to explain and explore without fear of being judged.

When we started, we probably wouldn't have said that education was one of the reasons we wanted to start the group, but we like the fact that we've learned a lot from each other along the way. All education, happening within a group like ours, is fundamentally different from that provided by a clinical or NGO support service. First, it often 'happens' rather than being provided. Most education for consumers by consumers concerns basic questions, like what is mental illness, what is mental health and what might recovery, for me, look like. Another major topic concerns the 'side-effects' of treatment. These discussions take the form of enquiry rather than instruction, as members seek to clarify their own perceptions, of their experience, in the light of others' experiences and beliefs. As members of the wider Australian community, members share many of the wider community's beliefs, fears and prejudices. Our own fears of and prejudices against mental illness are challenged by the

discussions that take place and sometimes reveal to us our own stigma which works against our 'recovery' - whatever those terms might mean to each of us.

There is also another side to education within consumer groups. Knowing how the mental health system works is important knowledge and plenty of formal information about it comes from official documents. For consumers, however, the system rarely seems to work the way the official version claims; members and visitors telling their stories helps people fill the gaps between rhetoric and lived reality. Most of all, we've shared ideas, knowledge and skills; everybody has skills and we found that, through the group, we have used and developed our existing skills and learned new ones from each other. Support provided among consumers (peer support) is totally different from that coming from any other place; giving support to others also greatly benefits how we feel about ourselves.

A code of ethics - do we need one and what might it look like?

A code of ethics, for consumers, would list those behaviours that would be seen as appropriate for consumers, who choose, in solidarity with other consumers, to join together with a common purpose. A *Code of Conduct* often arises out of a stated or unstated code of ethical behaviour and is used by a range of organisations and groups. The simplest code of ethics is the Golden Rule: "**Do unto others as you would have them do unto you.**"

When the subject of a Code of Conduct was brought up, at an early meeting of the Maine Connection, the strong response was that it was unnecessary: "*We're all adults, we know*

how to behave." While we haven't found a need, since then, to develop a Code of Conduct or Ethics, discussions about ethics are inevitable when talking about involuntary hospitalisation, treatments (including ECT) and medications. The following general points about what a Code of Ethics, for consumers, might need to address have all been made at various times in the group:

Confidentiality - *what's said in the group stays in the group; open discussion requires trust in each other. If people can't be assured of confidentiality, then what they speculate about or reveal about their past or their ambitions will be less useful to themselves and to the group.*

Respect - *for yourself and for all others; many consumers have experienced profound disrespect from service providers, family and friends. It's crucial that we respect each other. Our self-respect also often suffers following a diagnosis and it is important that each of us actively supports self-respect as well as acting respectfully to others.*

Tolerance - "***Think for yourselves and let others enjoy the privilege to do so too***." *People's experiences and beliefs result in a wide variety of views about all sorts of issues and events. Lively disagreement doesn't have to end in anger. It has a few times and we've offered people a lift home, if that's required, but they have to sort it out themselves - and generally, they have.*

Finding common ground - *It is important to keep in mind that, as consumers, we have much more in common than we have differences. We need to be united to achieve our shared goals and points of difference between us shouldn't get in the way of that.*

Honesty - *Hidden agendas can be very disruptive to any group; be 'upfront' about what you think, what you are hoping to achieve by a certain course of action, what you want from the group.*

Public responsibility - *Maintaining a respectable public image is important to the success of any consumer group, particularly if members want to have an influence on mental health policy and service delivery. Alcohol and illegal drug abuse will alienate many in the community and many potential members will stay away if the group has a reputation of condoning these.*

Peer support - *Simple. We support each other.*

Empathy - *All members have experienced distress of various kinds. Being able to relate other people's difficulties to periods in your own life is a powerful tool, in developing respect and tolerance within the group.*

Reported benefits of an inclusive, volunteer, community consumer group

Why do we believe that a community is the fastest and most effective way of finding ourselves again - not who we were, but who we have become? Active members of the Maine Connection were asked what they found useful about attending the group:

Knowing Yourself - *Getting diagnosed with a mental illness changes your life. A self-run support group provides a regular opportunity to think and talk about how you've changed and how your world has changed. Other people's stories and reflections help you understand your own place in the world.*

Knowledge of Mental Illness, Mental Health & Recovery - *Mental illness, mental health and recovery are all very loosely defined and there is plenty of argument about the definitions used. There are no physical tests to determine mental illness or mental health and recovery means different things to each of us. Informal discussion groups help people understand and define their own levels of distress and well-being and enable them to make decisions about their own recovery journey.*

Knowledge of the system - Improving mental health services - *Discussions about our own circumstances and those of others, plus stories of our experiences with the mental health system, invariably raise ideas about ways in which the system could be improved. They also help people form ideas about ways of minimising their own risk of relapse into un-wellness. The availability of advocacy as well as information speeds this process up.*

Normalising your condition - *Stigma and its more punishing offspring prejudice and discrimination stem from fear and mistrust of difference; increasingly it is clear that mental illness is more the rule than the exception in society and that it is the **extent of distress, experienced** by people, rather than the existence of **symptoms** which determines whether or not an individual receives a diagnosis. Freely discussing symptoms, medications, side-effects and the experience of mental illness can work wonders in removing that sense of difference.*

Regaining control of our lives - *One of the most distressing effects of a diagnosis of mental illness is loss of trust in ourselves; in many cases, other people lose trust in us too and, as a result, we may lose some control over our lives. Clinical and non-clinical services add to this sense of*

not being in control by the use of involuntary treatment and requiring people to follow their programs to receive a service.

Building self-confidence and esteem - *Self-confidence and self-esteem are based on our perceptions of ourselves. If we have lost those, through the diagnosis of mental illness and all its consequences, we need to develop new ways of 'seeing' ourselves and of understanding who we have become.*

Developing a community - *Communities take time to develop; despite members' insistence on inclusiveness, it took more than 12 months before we were confident enough, that new members wouldn't 'take us over,' that we could print and distribute flyers advertising our existence and welcome new people. Much of that time was spent in refining our ideas about what's been written above and determining what we wanted the Maine Connection to be.*

Rebuilding social networks - *Consumer communities may often be necessary as part of re-establishing yourself in the world, but it is rarely enough. Many of us have developed a belief that the wider community has rejected us and until our social networks branch out into that wider society, we can't realise our potential. For many, stepping outside the consumer community is best done with friends. We found that bringing the community into the Maine Connection whenever we can has worked for us.*

Creating a safe place for ourselves - *Creating a feeling of safety for people is essential; sharing food initiates contact and is familiar and welcoming. Confidentiality ("What's said in the group stays in the group") is essential for people to feel safe. A friendly environment, casual and informal talk, including everyone in conversation, tolerating different points of view, respectful behaviour by and to everyone, are simple but effective ingredients in developing a feeling of safety.*

Exercising your sense of humour - *Laughter is therapeutic and consumer support groups ought, above all, to be fun.*

Endnotes

52. Eg. more than 300 people have attended at least one meeting of the group, 93 having been potential or actual members, 99 paid workers, 65 family/friends, 63 visiting consumers and 7 volunteer alternative health practitioners.

{ *There are Therapy Groups and then there are… groups* }

Ann Tullgren

There are Therapy Groups and then there are… groups

What makes a group transformative and exciting – from the perspective of those with lived experience? What renders a group effective and seen to deliver measurable, evidence-based outcomes – from the perspective of the clinician? Why are these often so different?

Older consumers may have experienced many different types of group over the years; I've been in encounter groups where all is bared and emotion is viscerally felt so that catharsis may be achieved. I've taken part in groups informed by *Transactional Analysis* and others by *Gestalt Theory*. Then there are *psycho-educational* groups that seek to inform and put structure around experience and assist with coping (there're a bit of a favourite with carers).   A more recent 'flavour of the month' are *Cognitive Behavioural* and *Mindfulness* therapies, e.g. Acceptance and Commitment Therapy, even a blend of these, called MiCBT. *Dialectical Behavioural Therapy* groups are designed for those with trauma-related conditions and programs based on psychoanalytic principles continue to be offered. This is not meant to be a comprehensive list but, it demonstrates the multiplicity of groups and the different types of 'experts' delivering them, many of whom disagree with others! And who knows what else an adventurous PhD student or guru-in-the-making will dream up…

How can consumers navigate the group-work marketplace and determine what might suit them best? Even risking being accused of cynicism, there's always the quick decision based on the quality of tissues, the noisiness or effectiveness of the air conditioning, the size (and even presence) of windows in the room, whether the receptionist smiles at you and means

it, or whether the therapist meets with you before, discusses your needs and suggests the best group for you, without '*spruiking*' his or her own program based on generating profit; Twelve-Step groups (e.g. AA, NA, Grow) usually have the best tea-breaks, perhaps because they're peer-run... Underlying these idiosyncratic suggestions is the idea that a therapist, who cares for the therapeutic environment, will also care for consumers.

Groups have a particular magic that is less about the processes and the theories that underpin them and more about the relationship between participants and between participants and therapist. Consumers usually treat each other with dignity, humour, curiosity and empathy. There is wisdom in shared experience and mutual journeying towards a better place; the tone for such experiences is often set by the facilitator, particularly in the early stages of the group. Respectful relationships, sensitive to transactions of power, establish fertile ground for change to occur.

Rather than making an impersonal but comprehensive list of things to think about, I'd like to tell you what has worked for me and what I wish I'd known earlier in my journey, adding - of course - the inevitable comments and suggestions (sorry, I couldn't help myself!).

Selecting a group

While the word 'consumer' suggests the ability to shop around, compare programs and exercise informed choice, like most things in mental health, these are illusory; usually we are referred to a provider by a GP or psychiatrist, particularly when the referral forms part of a Mental Health Plan, in which Medicare pays (most of) the costs, even though the therapist is 'private'.[53] Different professions often have a list of members working locally, their areas of expertise, the theories they employ and whether they run groups or one-on-one therapy only. I've found that the information provided is usually very cursory and certainly not comprehensive and not really conducive to informed choice.

Reflecting on a group I was referred to recently; I was so grateful to be accepted that I didn't do due diligence for myself. This turned out to be a psycho-educational group, run according to eclectic 'pick 'n mix' principles (a bit of this and a bit of that or '*50 ways to leave your lover, become more successful, lose weight and become empowered*!'). Some suggestions conflicted with others and this led to a frustrating and confusing experience. The facilitator ran the group using a chalk and talk method (mostly one way), reminding me of lessons at school where the teachers taught and we listened (sort of...). No power points or interactive white boards, with the ability to print-off notes, were used. To me, it lacked coherence; keeping track of what was being said was difficult and at first I took notes but later asked for handouts although getting quality handouts took some negotiating.

Although I met the facilitator before starting the group, I didn't know what questions to ask and nor which program could work best for me. Some of the questions I wish I'd asked:

- How experienced are you?

- What qualifications do you have?

- Have you undertaken specific training in group work?

- Which theories do you work from?

- Do you have specific training in this theoretical position?

- Is the group closed or open? (a *closed* group has a set number of participants, who often attend for a specific period of time and no new members can join after the first group; an *open* group means that people can drop in and out and there may not be an end date).

- Where will the group be held and can I check out the room?

- If the group is being held in a hospital, will both in-patients and day patients attend and how does that affect people's experience?[54]

The therapist eventually recommended a different group, with a different therapist and the fit for me was brilliant; unfortunately, he moved on during the program leaving us suddenly high and dry, with lots of unfinished business. For me, the greatest sadness was that I didn't get to say goodbye to the other participants, whom I continue to think about.

Measuring success

Commonly participants are given a short standardised questionnaire before commencing the group, often measuring anxiety and depression. The psychologist running one group I was in asked me to fill out such a questionnaire in the interview before starting the group. When the scores were added up I was told I was depressed and anxious (duh???). She didn't tell me why I was asked to complete it (I assumed incorrectly that it was part of determining my eligibility for the group). I didn't ask about the uses to which it may be put (e.g. research, feedback to government or insurers about the effectiveness of the treatment), where the data would be stored, or who might see it. Interestingly, I wasn't asked to complete the same questionnaire on exiting the program.

Using the '*retrospectoscope*', I suspect that the intention was to determine the success of the group through an (hopeful) improvement in the pre- and post-group scores. If this was so, it would provide a blunt measure indeed; ignoring all other things going on in one's life that may influence us, in our recoveries, as well as the effectiveness of any medication or lifestyle changes, such as suddenly winning the lotto or being able to eat properly. It is also a top-down way of assessing suitability for a program, or its effectiveness and completely ignores any co-construction, between therapist and consumer, about what worked and what didn't. It was just another thing done to us, rather than with or alongside us.

Consumers end up being seen as responsible for failures of the group, such as staff not being respected. Responsibility for the shortcomings of the group may be deflected from the therapist, by blaming participants; similarly, any lack of expertise of staff or poor communication skills, their respect-deficit or indifferent sense of humour may be blamed on participants who are then perceived to be not committed, non-compliant or not working hard enough.

Use of students

Users, of all sorts of mental health services, will be familiar with the presence of students. I've been in this position too and find it galling, not to be asked to give informed consent for the presence of students (asking members of a group if it's OK for the student to sit in when s-he is already there is unlikely to elicit any 'no' responses). I also find it confronting when the student sits alongside the therapist, as if to say, '*Look here, I've already aligned myself with the power in this room*'; students who '*corporate-dress*' lack sensitivity towards consumers who may be unable to afford decent clothes, flash hair-cuts and gold jewellery.

Sometimes students are asked to run a group as part of their learning and assessment; these sessions can be well conducted, or not, or somewhere in the middle. I would argue that participants should not have to pay to attend a session run by a student, that Medicare should not be billed for this and that private health insurers should not be billed either. Universities do not pay therapists for supervising and training students and neither should we or insurers.

Ever had the misfortune of a student, whom you had once known or lectured when they were much younger, practicing 'on you'? I didn't think I would mind until it happened to me and it completely threw me off my already faulty balance. Power now rested with the student, who got to read my file and talk to the

psychologist about me and could go into rooms that were now denied me, because I was just a patient. We didn't even use the same toilet!

In some teaching hospitals or psych units, where students are being trained in particular skills or theories, the one-way mirror may be employed. This involves the group taking place in a room, where one wall has what appears to be a mirror and people on the other side of the mirror, in an adjoining room (e.g. teachers, senior clinicians who are often known as the 'reflecting team'), can observe the group and provide feedback to the student. The student sometimes wears a hearing device and the reflecting team can speak into a microphone to tell the student to try something different, which can result in a very disjointed experience for consumers. It is also ethically questionable because consumers are objectified and are prized for their 'use-value'. Very, very careful informed consent needs to be negotiated; if you are feeling at all fragile and suspicious, don't give permission.

Who pays?

While some group work programs are conducted by government-funded mental health services and at no cost to participants, others are billed to Medicare and/or health insurers. Consumers may be asked to make a gap payment, which raises a number of issues:

- How might these various sources of payment for groups change the relationship between the consumer and provider?

- If a consumer pays for all or part of the program does this change the contractual relationship between service provider and consumer? Does the consumer become an employer of the therapist and how might

this change the dynamic in the relationship? Does this entitle the consumer to be more discerning about what constitutes a quality service?

- How do Medicare or private health insurers ensure that the service meets their expectations of care? How might consumers be actively involved in assessing and reporting on quality service?

- If the group is being paid for by a private health insurer, all sorts of hidden costs may be involved. There are a multiplicity of different covers, some have co-contributions, others have excesses; the amount each cover pays for the same service can vary. Sometimes there are limits on the number of services provided in any one year. I've found that receptionists don't understand the complexities of this and if you ring the health fund, you may find that, unless you ask very specific questions, you may not get all the answers you need. My recommendation is to keep asking questions; keep ringing the health fund – a different person may give you a different answer (isn't that usually the case with Centrelink!). Here's a hint: make sure you ask what happens when the group isn't on one week because of a public holiday, because you may have to pay an additional excess yourself, as the individual services occurred more than one week apart. The Private Health Insurance Ombudsman has a useful website with Quarterly Bulletins documenting the number of complaints they received about which insurers, with a number of Fact Sheets and lots more information. You can contact them at http://www.phio.gov.au/

Involuntary groups

These are the groups you don't have an option about attending unless you want to be labelled non-compliant and difficult. They can occur in quite different venues.

Treatment Plans in Private Hospitals- *noun: I feel over-programmed already. There should be a programs limitation statute.*

MadQuarry Dictionary 2014:26

Patients in private hospitals often report feeling 'grouped-out of their brain' on the program carousel (9am – 10am Ward Meeting; 10am -10.30am Morning tea; 10.30am therapy group; LUNCH; 1pm Relaxation; 2pm- 4pm Art and craft). Private hospitals are compelled by the Funds to offer a program, in order to provide evidence that patients are doing more than sitting around having coffee and watching TV while waiting for an appointment with their psychiatrist and waiting even longer for the drugs to kick in.

In public hospitals, consumers often report their suspicion that groups are used for crowd control; hopefully, female patients will civilise the males (an argument used to establish co-ed schools); better behaved patients will tell the naughty ones to 'put a sock' in it. Groups, of course, give staff a chance for a coffee break, time for a ciggie... Ooops... I mean, catch up on their notes. Many consumers report that groups happen because that's what the program says, not that they may be useful or facilitate recovery. Because many patients, in public psychiatric units, are '*here one day and gone the next*' (FiFo – *fly in, fly out patients*), the therapeutic wisdom underpinning groups in acute care units is questionable, except, of course, for their crowd controlling properties. How can group therapy make sense when consumers are highly medicated? What chance is there of relaxation groups actually working, in the midst of a highly charged, scary and noisy environment! Seriously, public facilities are usually under-resourced, dislocated, patched together, having to cope with staff on shift work and various sorts of leave.

An interesting recent development is that private health insurers are being billed for some involuntary patients, who have private health insurance, who have been admitted to public hospitals.. Who then calls the shots about accountability? Will the same demands that insurers place on private hospitals, to run extensive therapy programmes, extend to public hospitals? What standards will be expected? Who will accredit the facility?

Therapy Participation Dichotomy- *noun The irony that public hospital in-patients are largely deprived of appropriate group therapy sessions, while private hospital patients are forced to attend groups 5 days a week, whether they want to or not*!

The MadQuarry Dictionary, 2014:26

Conclusions

Like so many psychiatric interventions, psychotherapeutic groups are too often constructed as hurdles to be jumped or endeavours to fail. Regardless of the particularity of the method, the very fact that the psychotherapist is not a group member sets up a potential for status conflict. Although some consumers accept this as part of the deal and are able to work within boundaries not of their making and structures not under their control, others cannot. This is not a personal flaw.

My own experience of DBT (Dialectical Behaviour Therapy) informs my question: after attempting to organise a consciousness-raising group to discuss the causative role of sexual violence and distributing fliers (around the group) that proudly defamed Charcot, Breuer and Freud et al., I was told, "we are not political here…" My actions were deemed 'therapy interfering behaviours' which, at least, seemed to lead to a comprehensive and personalised discharge plan … (Emerson 2006:3)

The problems of flawed process are often seen as failures of individual people, regardless of how carefully this is expressed. People are seen to lack commitment. Power, when theorised, can be seen as a tool rather than a problem. These issues escalate when people are forced to participate in groups they did not choose and do not want or when people are required to sign contractual agreements in order to participate. Therapeutic groups can work for consumers when relationships are fostered which enable all (including facilitators) to question, change, laugh, support and challenge each other.

Endnotes

53. Federal Government: Better Access to Mental Health - Information about Medicare rebates available to patients for selected mental health services provided by GPs, psychiatrists, psychologists and eligible social workers and occupational therapists.http://www.health.gov.au/internet/main/publishing.nsf/content/mental-ba-fact-pat

54. A couple of years ago I attended a group in a private hospital as a day patient. Group members were both in-patients and day patients. I found this really frustrating because participants were in various stages of recovery, it wasn't possible to predict who would be there from week to week and, most frustratingly, people kept going in and out of the group for appointments with their psychiatrist! The morning tea, however, was very nice until the budget ran dry!

{ *Working with therapeutic groups* }

Fiona McDermott

Working with therapeutic groups

To say that this chapter is about working with therapeutic groups already poses a challenge. All groups have the potential to be therapeutic, if they make participants feel better about themselves, if and how, the issues that brought them to the group have been addressed or tackled and the outcomes that emerged from being part of the group. And importantly, all groups are therapeutic, if the purposes which were their focus have been achieved.

I will discuss two particular kinds of therapeutic groups – a mutual aid group for women with advanced breast cancer and a psychoanalytically-oriented psychotherapy group for people dealing with depression, anxiety and more general 'problems in living'. Having categorised them as '*therapeutic*' groups, I will show how purposes, structure and leadership roles are designed in order to achieve, in different ways, some of the therapeutic goals suggested in the previous paragraph. The chapter ends with some suggestions about setting up and working with groups like these.

Two therapeutic groups:

'*Thursday Girls*' is a group for women, with advanced breast cancer, which has been meeting weekly for almost twenty years; originally established in 1997 as a research intervention designed to, test out the proposition, that a group providing expressive-supportive therapy extended the lives, improved quality of life and reduced depression experienced by women, with this disease which has been extensively studied. Results indicated that improved quality of life and a reduction in depression resulted, whilst the 'jury is still out' about life extension[55]. The results

were an important incentive for the continuation of the *Thursday Girls* after the trial finished, strengthened by the very positive feedback from participants and their demand for its continuation. The women named the group the '*Thursday Girls*' because they met – and continue to meet – on that weekday; they also published a book describing their experience in this group – '*The Thursday Girls*' (2004).

The group meets weekly for one hour, members staying on for a social catch-up over morning tea. There are two leaders, a psychologist and a social worker, neither of whom has the disease. The criterion for membership is that participants have advanced (or metastatic) breast cancer. There is no agenda, other than the issues and concerns that participants bring for discussion each week. It is an open, long-term group, participants joining and leaving at any time. Most remain in the group for months and years, often only leaving when death intervenes.

The psychoanalytically-oriented psychotherapy group, for people experiencing depression and anxiety, is also a long term, open group not exceeding 7 – 9 members; men and women participate and ages range from mid-20s to mid-60s. People join and leave at different times,

with an average length of stay being years rather than months. There are two group therapists, a psychologist and a social worker.

The group meets weekly for 1.15 hours; there is no set agenda - what is talked about depends on what members wish to share. There are strict boundaries in place, guidelines emphasising confidentiality and (in contrast to the Thursday Girls) that members do not meet outside the group. There are several reasons for this: preventing the formation of sub-groups, which can be detrimental to this kind of group; ensuring that the group remains a safe place for members and that the group is seen as a '*work place*' rather than a social activity.

Group processes and dynamics:

As is clear from the descriptions, the two groups have substantial differences; but they also have things in common – and these they share with many groups. Each has a purpose, a structure, is aimed at a particular membership, is led by trained group leaders or facilitators (they are not self-help or peer-led), arises from and exemplifies a theoretical base, together creating the '*group dynamics*', the sometimes intangible, but always present and always influential, processes, relationships, emotions, meanings and interpretations which emerge when a number of people get together. They give a group its characteristic 'flavour' and sense of animation and movement and they are enacted, in all groups, primarily through talk, through telling stories, doing activities collectively, reflecting on these events and moments, trying to make sense of them. In concert with the members, the group leader's task is to strategically use such processes and dynamics to achieve the group's purpose and the purposes individual members bring.

Importantly, similar events and activities (talk, actions, tasks, exchange, communication with others and body language) are interpreted differently, depending on one's theoretical perspective. Issues are problematised and theorised and their representation in the espoused purpose identified for each group is treated differently. Although groups may be formed for a great range of purposes and may take a variety of forms, their common characteristic is that they create processes, but what they *mean* is open to interpretation.

Some of the differences informing the two groups mentioned are discussed below.

Theory and Purpose:

The decision to form a group, rather than work on an issue or task, independently suggests that, at some level, we believe that the purpose, we have in mind, will be achieved best by the collective involvement of a number of people. When we articulate its purpose, we specify the kind of group we want to form or join so that its design or form derives from that purpose. Purpose determines the kinds of people who might be selected or wish to join, the kind of leadership it will have, the type of group it will be (Douglas 2000; Magen in Meyer & Maitaini 1995).

The *Thursday Girls* group has 7 espoused purposes, relating primarily to a focus on dealing with the recurrence of cancer and the advent of death:

• Build bonds between members, through both participation in the group and in socializing outside the group with others, who understand better than anyone else, what each person is dealing with,

- Express emotions, especially the difficult emotions of anger and sadness, in a safe and contained group space,

- Detoxify death and dying, that is, to reduce fear and uncertainty, especially about treatments and their effects, ensuring that necessary tasks, such as preparing family members for loss and for 'going on' are addressed,

- Redefine life's priorities, in the light of a perhaps shortened life expectancy, for example in relation to employment and financial matters,

- Increase support of family and friends, in recognition that such support is a powerful element in building resilience

- Improve doctor-patient relationship by, for example, increasing confidence in asking questions of medical professionals, or exploring the range of treatments available,

- Improve coping skills by, for example, learning from one another about managing the disease or different treatments, which may be beneficial in reducing anxiety and depression

The theoretical base underpinning the *Thursday Girls* is *Systems Theory* (with elements of existential and humanist perspectives). It is a mutual aid group, the purpose of which is to use the resources of the group as the context for change, support and mutual benefit. Mutual aid groups work from a perspective in which the characteristics of systems – interaction and flow, a tendency towards the maintenance of equilibrium, containment within boundaries separating the inside from the outside – are helpful in understanding what might be going on

in the group. Shulman (2010) identified ten ways in which a group as a mutual aid system works and through which the members help each other. These are by:

- Sharing thoughts, feelings, ideas

- Establishing dialogue and a dialectical process

- Entering taboo areas, for example, regarding sexuality or death which are often not able to be talked about elsewhere

- Recognising that members are 'all-in-same-boat' and deriving comfort from this

- Developing a universal perspective, shared by group members, for example, that the group can support its members enduring life-threatening illness

- Offering mutual support where possible

- Making mutual demand when the need arises

- Providing space in the group for individual problem solving

- Providing space in the group for rehearsal, that is, trying out solutions before applying them in 'real life'

- Becoming more resilient by recognizing the 'strengths-in-numbers' which group participation represents.

The purpose, underpinning the *psychoanalytically-oriented* psychotherapy group, is drawn from a theory proposing that much of what motivates and sustains us and our behaviour may be outside our awareness. The purpose of the group is to develop insight, which may lead to changes in thinking and behaviour. In the group, participants bring together their individual motives, personalities, mental processes and behaviours.

By talking about these and hearing the responses and interpretations of others, self-understanding may occur, as what has previously been outside awareness is drawn into consciousness.

Psychoanalytic Theory (Anthony 1971; Toseland & Rivas 1998; Corey 2000) understands the family as the individual's first experience of a group; the original family was the site for the experience of conflict, as the individual negotiates psychosexual stages of development and maturation. In the group, these early family experiences are re-enacted. The concepts of transference and counter-transference (referring to the dynamic, often unconscious impact emerging between individuals and between individuals and the leader) are important, in understanding the ways in which individuals re-encounter unresolved conflicts and are assisted in linking these struggles to their current behaviour. The purpose of the group is for individuals to gain insight, into the causes and manifestations of these unresolved conflicts, through their engagement with others, strengthening their interpersonal skills and adaptive capacities through the group process.

Group structure:

As we have noted, both groups are long-term and open, meaning that members join and leave at different times; in fact, there is no '*finishing date*' for either group. Such an open structure can be appropriate, where participants are working on issues shared in common but, which have different significance for them, e.g. chronic or terminal illness, depression, anxiety. In the *Thursday Girls*, where the purpose of the group is to assist people in confronting anxiety-provoking and existential issues (such as life and death, pain, coping with

chronic illness), an open group allows support to develop and be maintained, even as the membership changes through illness or the death of participants (Spiegel & Spira 1991; McDermott, Hill & Morgan 2009). In the *psychoanalytically-oriented* psychotherapy group, the development of insight does not usually happen quickly and many members have battled their difficulties over many years. It makes sense that, it will therefore take time to address these difficulties and for participants to reframe their lives, in different, more hopeful ways.

Leadership:

Group leadership can be understood and practiced in many different ways, all of which depend upon the purpose and the theoretical base of the group. Leadership refers to the capacity to influence group participants and the development of the group itself; when saying 'we are influencing something', we are referring to the ability to make a difference in some way, to change things inside and outside the group. Toseland and Rivas (1998:104) usefully identify three categories, of skills, that the leader brings to the task which have relevance to almost every group:

- Facilitating group processes by such actions as involving members, focusing the group's communication and clarifying the content which is emerging

- Data gathering and assessment: this requires the leader to ensure that members' thoughts and feelings are understood by requesting information or asking questions

- Action: at times, the group leader may provide support or challenge and confront members to assist them in moving forward in tackling and resolving the difficulties they encounter.

We might add the leader's conceptual and organisational skills, evident in the clarity with which the group's purpose is articulated and the process of the group as they set out to achieve this.

In relation to the *Thursday Girls* group, conceptualised as a system, the leader's role is that of '*system manager*', mediating between individuals and the group and other external systems, to establish a helping system of benefit to all. In the *psychoanalytically-oriented* psychotherapy group, leaders focus their attention on how individuals work together in the group, in collectively achieving the individual aims and needs of members, facilitating interpersonal interaction and offering interpretations and information to assist understanding.

Both groups tend to be relatively unstructured, group members bringing their own agenda and being encouraged to speak as freely as possible about any issues or concerns they have. In the *Thursday Girls*, the leaders' role is to maintain awareness of the primary purposes of the group, concentrating on ensuring that the group is a place where difficult issues and emotions can be safely brought, using their skills to strengthen the bonds that members form and to build their resilience. Leaders and members alike have to learn to deal with whatever comes up, e.g. the impact of the disease on children and partners, the unexpectedly quick progression of illness for some women not-responding to traditional treatment.

In the *psychoanalytically-oriented* psychotherapy group, group leaders take a somewhat non-interactive and distant stance, facilitating members' projections and fantasies, which become evident in transference and counter-transference reactions. The group leader's role is to offer interpretations, which focus on these unconscious productions, enabling members' anxieties and distortions to become visible and, in this way, assist them to gain insight.

'Thinking Group'

What underpins all aspects of the group leaders' role is the importance of their viewing the group 'as a whole', *an entity which has most likely taken on a 'life of its own'*, a dynamic and animated network of people, their desires, emotions, wishes and intentions brought together in time and space. Group leaders are not working with various individuals who are 'in' a group but, first and foremost, 'as' a group: the primary focus is on the collective identity which makes up what is thought of as a group: thus, groupwork *by definition* is working with a group, hence the key skill is the leader's capacity to '*think group*'.

Advocating for group workers to '*Think Group*', one needs to keep in mind that, while groups are comprised of individuals, their coming together may enable the expression of powerful forces, reinforcing a sense of commonality and solidarity, the building blocks for the development of trust. Trust and its counterpart, *reciprocity amongst members*, may establish the bonds which serve to enable them to achieve their individual and common goals and the group worker's task is to nurture such development. By '*thinking group*' rather than '*thinking individuals*', the group worker positions him/herself to see and enhance these elements for the wellbeing of the whole, a capacity central across all kinds of groups - psychotherapy, psychoeducational, mutual aid, social action.

Listening:

The capacity to *listen* is a key leadership skill, basic to any therapeutic endeavour; theoretical knowledge provides the mental and cognitive constructs to thinking, but it is the capacity to listen – and hear – which determines how we use theories. The 'baseline' of all therapeutic work is skilled listening; therapeutic listening, provided through training and experience, entails hearing what is spoken *and* unspoken; it enables group leaders to derive meaning from what is communicated by the group members and can facilitate a greater understanding and re-construction of meaning which can prove helpful in managing life's challenges, be they a life-threatening illness or emotional distress (McDermott, Hill and Morgan 2012).

Getting people together in therapeutic groups widens the availability of therapeutic contributions and enables participants to get a range of perspectives and understandings of their communications and situations, assisting them in understanding or working with their own issues, developing their ability to step back, heal themselves and learn how to reflect. Briefly, the group leaders' goal for group participants is to develop their capacities as interpretive and reflective listeners and increasing the number of thoughts available to them about problematic situations; group leaders thus *model* 'good' listening.

Handling problems:

All groups experience moments of conflict and disagreement and often it is expected that group leaders be skilled in resolving these, an expectation which raises the anxiety of novice group leaders. Conflicts and problems can emerge from anywhere and are frequently unexpected; group leaders - and group members - are fearful that conflict can be problematic and destructive, not just to the survival of the group itself but to the individual members' emotional wellbeing. However, as a '*rule of thumb*', the group leader might want to recognise that the emergence of conflict 'belongs' to the group-as-a-whole and finding solutions is a task for the group-as-a-whole, another reason why '*thinking group*' is such an essential skill.

What kinds of solutions emerge depend on the kind of group, which, in turn, determines how conflict is interpreted (Benjamin et al 1997; Conyne 1999; Forsyth 1999; Toseland & Rivas 1998). In a mutual aid group such as the *Thursday Girls*, the leaders' efforts would be directed towards understanding its meaning and impact in relation to the group's purpose and to the group-as-a-whole. In a psychoanalytically-oriented psychotherapy group, conflict might be seen as an opportunity, for all members, to explore and try to better understand the factors leading to conflict and how these affect the emotional lives of group members.

Do therapeutic groups work?

Researching outcomes for ongoing, open therapeutic groups is a difficult enterprise, given their constantly changing and evolving nature, the length of time during which participants may join them, the differing goals and purposes that members and leaders may have (McDermott 2003; 2004). Block and Aveline (1996) noted nine elements providing useful guidelines to evaluate the outcomes of therapeutic groups: cohesiveness; learning from

interpersonal action; insight; universality; hope; altruism; guidance; vicarious learning; catharsis and self-disclosure. The extent to which these are present is said to be indicative of the nature of the group's impact on participants.

However, those who have participated in therapeutic groups are an important source for understanding 'what worked' for them – and maybe they should have the last word. When asked what they considered represented a 'good' group, participants said (McDermott 2002):

... a group that's really important to its members..

... (a group that) gives you proof of progress, validates skills, confidence, self-esteem...

... a group where there's good bonding and caring and support - compassion...

... (a group which is) a mutual support and a mutual challenge...

... (a group which gives members) opportunities to see themselves reflected back by the group - this gives them strength...

Working with a therapeutic group:

To finish, some ideas about working with a long-term open therapeutic group, such as the two described above:

- Be clear about what purpose(s) you think a long-term open therapeutic group can meet - and what purposes are best met by other kinds of groups

- How does a long-term open group differ from a short-term closed group in terms of particular challenges it poses, e.g. introducing new members at different times; fare-welling members at different times; dealing with boundary issues etc.

- Training is vital

- Regular supervision is a necessity

- Conflict? Expect it; address it!

- The group is the members' group and problems in group are problems for the group to address (with the leaders' help):

- Work with the 'group as a whole,' as distinct from doing work with individuals in a group

- Hone your listening capabilities

Endnotes

55. (Anderson, B.L. 2002; Beacham, B., Hill, C., McDermott, F., O'Brien, M., Turner, J.2005; Bordeleau, L., Szalai, J.P., Ennis, M., Leszcz, M., Speca, M., Sela, R., Doll, R., Chochinov, H.M., Navarro, M., Arnold, A., Pritchard, K.I., Bezjak, A., Llewellyn-Thomas, H.A., Sawka, C.A., Goodwin, P.J., 2003; Cunningham, A.J., Edmonds, C.V.I., Jenkins, G.P., Pollack, H., Lockwood, C.A., Warr, D. 1998 Edelman, S., Bell, D.R., Kidman, A. 1999; Edmonds, C.V.I., Lockwood, G.A., Cunningham, A.J. 1999; Hill, C., Kisssane, D., McDermott, F. 2004; Kissane, D.W., Grabsch, B. Clarke, D.M., Christie, G., Clifton, D., Gold, S., Hill, C., Morgan, A., McDermott, F., Smith, G.C. 2004; Lachman, L. 2002; Lillquist, P.P. and Abramson, J.S. 2002; Llewelyn, P., Murray, K., Johnston, M., Johnston, W., Preece, E., Dewar, A. 1999)

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{ *Facilitating 'Hearing Voices'*
Groups }

Voices Vic – Prahran
Mission Uniting Care

Facilitating 'Hearing Voices' Groups

Values and historical basis

'Hearing voices' groups emerged as Professor Marius Romme and Dr Sandra Escher found that many people hear voices without distress or feeling the need to seek mental health services. They interviewed many 'voice hearer's – those coping and those being in distress and those with a diagnosis.

They found that coping 'voice hearers' have different skills, beliefs and supports compared to those who live with often extreme distress. People coping well with voices had:

- Higher self-esteem

- An explanatory framework for the voices

- Ease when discussing the voices with others

- Ability to more often communicate with the voices

- More social and supportive connections

- Ability to set limits with the voices

- Ability to selectively listen to the voices

- Know-how in addressing past traumas and emotional difficulties.

According to Marius Romme "*Many voices can be unthreatening and even positive. It's wrong to turn this into a shameful problem, which people either feel they have to deny or to take medication to suppress.*" Many 'voice hearers' who suffer greatly from their voices, do not readily get all their needs met by psychiatric services; specialised *Hearing Voices Groups* aim to support voices hearers who want to understand and work with their voices, whether they are positive or negative and to learn new coping skills.

Voices Vic has run *Hearing Voices Groups* since 2005 and is proud to support other organisations, across Victoria, to create opportunities for collaboration and recovery; we work in partnership with other *Hearing Voices Networks* in Australia and overseas. Our groups were created as a response, to the growing understanding that shaming people who hear voices doesn't enable them to live decent lives. Forcing a label on a person, or forcing him/her to agree that they have a mental illness and that there's no cure isn't helpful and certainly does not give any hope to thrive, which is why 70.9% of people, diagnosed with psychosis have inadequate and unsustainable recovery outcomes. 'Voices hearers' lives become full of repeated hospitalisations, loss of personal freedoms (involuntary treatment), powerful medications, debilitating side-effects of psychiatric medicines (obesity, diabetes, tardive dyskinesia…), reduced life expectancy, frequent fear and distress, social isolation, unemployment and extensive poverty, unsafe or unstable housing, stigma and discrimination, pervasive hopelessness.

Hearing Voices Groups fill a void in the services other groups offer; it is a human need to have conversations, about what is happening or

felt to be going on in one's life. There is also a strong need in humans to be heard, to gain some kind of understanding, connection and validation when talking about feelings, beliefs and circumstances. For people who hear voices, these needs are no different; after all, voice hearing is a normal human experience and understanding that a person's voices are **real** is essential to giving him/her enough respect to live a decent life and connect well with his/her community. Acknowledging that the voices are real and building relationships with them are key components of a *Hearing Voices Group*.

In *Hearing Voices Groups*, all beliefs are accepted based on the diversity of humanity and its various cultures and contexts and individual needs. The beauty of *Hearing Voices Groups* is in sharing that diversity, allowing for people to say what works and doesn't work for them when trying to cope with their voices. Speaking in first-person terms and acknowledging one's own beliefs, rather than using second- or third-person modes to describe someone else's experience, allows people to speak their own truth and avoid imposing on another's belief.

Groups recognise that 'voice hearers' are experts in their own experience and that recovery is not necessarily the absence of voices, but the ability to live a meaningful life with minimal distress. Groups need to be safe and inclusive spaces, in which 'voice hearers' can share experiences, learn new ways to understand, cope and live and create a powerful sense of hope and possibility. Hundreds of *Hearing Voices Groups* exist around the world, in which 'voice hearers' support each other to make meaningful recoveries on their own terms.

Starting a group in your community

Starting a *Hearing Voices Group* does take some organising, as well as tenacity, understanding and/or training in the voice hearing experience, empathy and commitment. At Voices Vic, we have two facilitators, one of whom at least is a 'voice hearer.' Groups transition to being facilitated by 'voice hearers' only. Our experience is that well-working groups meet weekly; group members are not expected to turn up every week, so sometimes as many as 25 different people will attend a group over the period of a year, but not all at once. In our experience, anywhere from 3 to 12 members can work well as a group.

It is up to the group to decide whether to make the group a closed group, or not. There are a number of *Hearing Voices Groups* that are closed, mostly in hospital out-patients settings. The middle of the week is a good day for a group to meet (so support is available next day) and it's best not to run groups too early or too late in the day (4pm – 6pm or 1pm - 3pm often works well). Groups generally run for about 1½ hours, followed by socialising (30 minutes at a coffee shop). Meetings are best held in the community, a library, a neighbourhood house or community hall rather than a mental health service.

It is really important to provide a safe place for 'voice hearers' to get together, so that they can explore their voice hearing experiences. When looking at potential meeting places think about:

• What is the space we want to create?

• What does the space do for 'voice-hearers'; for people?

- What's on walls? (This is important when the environment is a non-specific space, such as a library.)

- Time of day the space is available? (Think about effects of medication and other issues such as night travel.)

When deciding on who will facilitate, bear in mind that a greater connection and understanding exists between people with similar experiences; 'voice hearers' have been often experienced severe discrimination, for talking about their experiences, by those who don't hear voices. That's why having a facilitator, with lived-experience, can mean the difference between some 'voice hearers' being able to speak or or not at all. Trust can take a long time to grow in a group where the facilitator does not hear voices. If you think about a women's group being facilitated by a man, or cancer survivor group being facilitated by someone who has never experienced cancer… you'll recognise the strong need, for at least, one facilitator with lived-experience. So there is a preference for having a 'voice hearer' to facilitate a group, rather than someone who just has some other experiences and good empathy/listening skills, but who cannot really relate to voice hearing; Voices Vic, however, does not have a strict rule on this.

Developing and Communication within the Group

In the words of Jacqui Dillon (chair of the UK *Hearing Voices Network*):

"*The aim of the group facilitator is to lead by listening. This means that, wherever possible, the group as a collective makes decisions about direction, activities, changes, etc. It is the facilitator's role to enable this process. A key part to this role is to magnify the voices of people who are not normally listened to, by emphasising the belief that each person in the group has a deep wisdom and expertise about ways of managing and dealing with problems.*"

The group offers an opportunity to develop skills, beliefs and supports, as well as to explore and understand voice hearing experiences. Its focus is on social inclusion, also acting as a support network. The facilitator's role is to create a safe space, to explore voice hearing amongst peers, to draw out experiences, enable discussions, while providing validation and normalisation, with the group holding the wisdom. The normalisation of the voice hearing experience, for the 'voice hearer,' is an extremely powerful experience, often beginning the recovery journey.

People who hear voices, generally have been made to feel ashamed and afraid of themselves; their core-beliefs have been vilified, their personality has been called "*disordered*" and "*diseased*". It's a lot for a 'non-voice hearer' to understand, because so much of what a voice hearer has tried to talk about previously has been shut down and declared to be nonsense. It is wonderful when people, who don't hear voices, make an effort to understand, be open and willing to listen and recognise what is needed: a willingness to learn, without Band-Aid-methods and bigotry creeping in. For instance, telling someone they "*don't make sense*", is a judgemental phrase that doesn't enable a person to communicate, rather aggravating his/her despair. Instead, a facilitator should try to find out what does make sense, or admit needing extra help in understanding what was meant.

The impulse for facilitators to solve a problem or rescue someone in distress is well-meant – but in a voice hearing group, experiences are shared and different members' coping strategies are listened to. Individual members will test or try other suggested coping strategies and see what works for them. The group empowers members, building a tool box of coping skills others in the group can use. When rescuing someone, we put them in the role of victim and take away opportunities to build skills and self-esteem.

What is unique about voice hearing groups?

A variety of experiences

'Voice hearing' is not limited to one type of experience, such as verbal, sound-related intrusions on a person's identity; groups will talk differently about other unusual experiences, e.g. some will discuss sense-memory intrusions, with others talking about their spiritual nature. A huge variety of experience makes up the unique nature of 'voice hearing' groups.

Voices are often symbolic and can manifest visually, through tactile means, through taste or smell or all those senses; if words or sounds are heard, the tone is often what affects 'voice hearers' most. Emotions are often a very distressful part of hearing voices, although they can also contain elated or comforting emotions, essential to coping with social hardships. Likewise, being distracted by voices can allay loneliness but can also prevent a person from having a successful career, self-esteem is often a point of discussion in *Hearing Voices Groups.* There are many different ways of interpreting particular voices, each experience being unique to

the individual experiencing it; there are, however, many similar experiences and opinions that 'voice hearers' find useful to have discussions about.

What's fairly normal for a 'voice hearer' is that, commonly, people think they are in need of the CAT team, a threat which can make people simply close up. This is why it's a great relief for many 'voice hearers,' attending *Hearing Voices Groups,* to know that they will not be subjected to an over-the-top panic, when mentioning something, they probably wanted to talk about for years, but feared the consequences. Voices Vic groups have never had to call for assistance; we work together to reduce the stress of hearing voices through validation and enabling people to recognise their boundaries. For facilitators who don't hear voices, it is recommended to have some training in working with people who hear voices.

The Hearing Voices Approach

1. What is unreasonably taboo to talk about in mainstream society is what *Hearing Voices Groups* have conversations about.

2. The *Hearing Voices Groups* are open to anyone who hears voices or has other sensory experiences that other people do not. The two most important beliefs or values of the group are that, the experiences a member has are real and that we are not there to, necessarily, get rid of the voices.

3. In a *Hearing Voices Group* there are no observers. Facilitators, carers or visitors, who come regularly to a group, should tell their stories about their experiences, with people in their lives who hear voices; this gives the group an inclusive feel and can add an aspect of normalising some day-to-day

experiences that everyone has whether 'voice hearer' or not.

4. Confidentiality is a must; what is said in the group stays in the group. Having this value repeated, when new members enter the group, reinforces a sense of trust, allowing people to have conversations they may never have felt safe to have before. The feeling of being safe to talk can take time for some group members and there are no expectations on members to share with the group till they are ready to.

5. Group members can explore new ways of coping and living, the aim being not to get rid of voices but to explore ways they can best live with them. Some benefits of coming to a *Hearing Voices Group* may include: feeling less alone; increased confidence and mastery over voices; increased understanding of voices; new strategies to reduce distress; opportunities to support others as well as receiving support.

6. Understanding that the voices are real, on whatever basis the voice hearer wishes to discuss them, is essential to the *Hearing Voices Approach*. Voice hearing being real means that the content of voices often contains clues to resolving feelings of distress: traumatic life experiences; emotions due to social circumstances; time of year or memorable days relating to grief; metaphorical/symbolic unresolved guilt, shame and victimisation.

7. Talking about coping strategies is part of every group and some sessions can explicitly focus on a few different strategies and test them out. Facilitators can source coping strategies from the Voices Vic website or any of the Hearing Voices books and bring lists of strategies to the group to discuss and try out, get the group to generate their own strategies, or extract them from recovery stories.

Catering for everyone through Group Values

Group facilitators provide a place where people primarily meet to discuss their voices, coping strategies and how they are travelling; members should be allowed to talk about what they most need to have a conversation about. The facilitator needs to ensure the groups remains focussed on their purpose and does not 'go off topic', as members know they are meeting to talk about voices, which are quite often related to other aspects of a person's life.

Most groups benefit from jointly agreeing, in the first week, on group values; they create a sense of safety through boundaries and facilitators can feel that something the group agrees on, is in place to make everyone feel more comfortable about sharing their experiences. A big part of the facilitator role is finding the right balance. Catering for everyone, though, is not without difficulties, especially given that the telling of some causes of hearing voices can act as a trigger to other 'voice hearers.' Discussing ways of talking about abuse, neglect, being bullied and institutionalisation, without going into too much detail, is often incorporated into the values the group establishes. Ways of letting facilitators and group members know when a story is becoming upsetting, should also be discussed; for example, a group member would just move their chair a little back from the circle if feeling upset.

This is a basic and safety-first discussion: how do we look after ourselves and group members? It should be something everyone is happy with. Giving power to and understanding of members to ask for time-out, in a way that feels appropriate and natural to them, means they don't have to be alone in their suffering.

Building rapport, support and equality

Facilitators, while being central to the group and often also a 'voice hearer', should not dominate but rather reflect on topics already chosen by members. In balancing the facilitator role, Voice Vic suggest about 80% devoted to a **supportive focus** (draw out experiences and discussion; provide validation and normalisation; be a role model in respecting differing beliefs; ensure people feel included and safe) and 20% to a **guiding focus** (introduce new ideas and strategies from the *Hearing Voices Approach*; do creative explorations in artistic media; use informative/educative content, including short stories or information from books, DVDs/internet about recovery - sharing stories such as these is a great way to get the group talking.)

Topics of interest arise from group members and can easily be followed up; it is important that facilitators allow the group to flow. The most important element is giving 'voice hearers' the opportunity to be heard; they should be encouraged to bring in their own art work, music, writing, or skills such as juggling to show other group members. Some 'voice hearers' may not want to share their experiences, which is okay too, because even listening to others share their stories will bring benefits. Never pressure people to talk if they don't want to, but ask questions if

people seem to need encouragement to speak (e.g. what have the voices been saying this week? Any changes in the voices this week? Any particularly difficult or successful situations with voices this week? What's your past experiences with voices? Want to reflect on anything from what the group has been saying?)

Grounding

There are good reasons to have two facilitators, first and foremost to have someone who can step outside with someone who needs some one-on-one time; this gives a person some privacy and time to talk through things or sit with a facilitator, knowing they care enough to spend time, making sure they get what they need to cope with what's overwhelming them. While this is happening, the co-facilitator is available to take care of the group process.

The facilitator's job is to listen, not only with their ears but with their eyes and anything else that makes sense; if a group feels 'discombobulated', it means that it's time to move about a bit. A shake out of limbs, doing a stretching exercise can get people grounded in time and place once more. This can be followed by a discussion about different ways of making sure we stay present; looking around at the building walls, or at the faces of people around you, moving the body, or using a stress-ball or plasticine to squeeze, are common methods to get grounded in the moment.

Having two facilitators is not only useful to assist a group member, but also in case one facilitator is unable to make it at the last minute or is running late. It is also important that facilitators have someone to debrief with, a role usually played by the co-facilitator. This assures confidentiality

while sharing any stress related to facilitating the group. By supporting each other, facilitating becomes an easier and more comfortable task. Mistakes do happen, but it helps if they can be talked through, so that people can move on rather than repeat them. Really, the worst mistake any facilitator can make is not to be him/herself.

If, for some reason, it is not possible to talk to a co-facilitator for a few weeks, one might try to debrief by writing a few notes, asking the following questions: How did it go? What was the participation level of the group? What themes emerged? What did you say that you wish you hadn't? What didn't you say that you wish you had? Is there any follow-up to be done? What are you going to do to take care of yourself in the next 24 hours?

Whether groups are facilitated by a worker, a 'voice hearer' or both, Voices Vic provides training and support, in the *Hearing Voices Approach,* to facilitators and they can debrief with the Voices Vic's Network Co-ordinator.

Overcoming fears of facilitating groups

Unusual experiences are fairly normal to the group, which is why they need to be opened up and explored rather than shut-down; it helps to engage group members in conversations by asking open questions and avoiding judgements: how has your week been in regards to your voices? Were the voices louder or softer? Did you notice any changes? How have you coped?

Other people in the group are likely to have similar experiences or would be able to relate; this, in turn, will help members to validate and normalise their experience – reducing distress. It doesn't matter what people believe – it does matter that

they have the opportunity to explore; facilitators can't make sense for them but can provide opportunities to do so.

It is not uncommon for a new member, joining a Voices group, to experience their voices becoming more active; welcoming their voices to the group is a good way of approaching this as groups are not about getting rid of the voices (although this may happen for some); it is about working with and understanding the relationship people have with their voices. Group wisdom enables the individual, to potentially see other points of view or, ways of explaining their perception, so their conversation can be more readily acceptable outside of the group. Everyone should be allowed to have a say, be heard and their perception must be validated.

While organisations running groups should make their own list of appropriate emergency numbers, it is useful to do this in consultation with group members, so they can nominate contacts. When someone is thought to be at risk of suicidal or violent behaviour, outside of *Hearing Voices Groups,* "*Duty of Care*" is often used as a reason for breaching confidentiality and contacting the CAT team, police or psychiatrist. Discussions about suicidal and violent voices can be common in *Hearing Voices Groups,* but it doesn't mean confidentiality should be breached on a regular basis; disclosing personal information can be a breach of UN Charter of Human Rights; we need to remember that:

• Someone hearing a voice making violent threats doesn't constitute a duty of care issue. People hear violent voices all the time without taking any action.

• People can intend to carry out violent actions and give no signs at all.

- Breaches of confidentiality are one of the greatest concerns of 'voice hearers' and can severely damage trust.

When a group member says "*the voices tell me to kill people*" or "*the voices tell me to die*", it's about context, rather than the words themselves. If a person has heard such voices for years and did nothing harmful, be respectful of what the person is actually saying and don't jump to conclusions, informed by totally different contexts you may have been part of at another time. Where possible, let the group discuss what might be going on for the person; in many cases, other members may have had a similar experience. Voices are often *metaphoric*; it's not the person that has to die but it can be something about him/her – some behaviour or some characteristic.

If the person needs some one-on-one time, one facilitator can leave and have a chat with the 'voice hearer' and listen, asking questions that allow him/her to talk through things to the point where they can gain some ground, through their own volition, as to what's really going on. The group member may want the support of a CAT team or ask the facilitator to ring a friend or just need the space to be listened to; being open to all possibilities is crucial.

To give an example; in one 'voice hearer's' experience, the voices said she wanted to die and that she wanted to kill everyone and these voices occasionally also would come out of her mouth. If people were present, she would immediately apologise, saying that's not what she wanted to say. She realised these voices came from several differences places, tangled into one, including a suicidal and threatening parent, an abusive partner, films and computer games. They were not her opinion, they were things around her in society that upset her or made her feel like she had at those times in her life where she'd been cornered and threatened. She felt blamed for these thoughts because she couldn't stop them. By challenging the voices, looking at the feelings behind the voices, the imagery and the subtext and talking this through with others, she was able to reconfigure the voices and use their energy for other purposes, instead of letting them get in the way of her ability to work.

Facilitators could ask members to share whether they had tried challenging a voice themselves; challenging helps people to see that voices don't always tell the truth and that they have more power than the voices. 'Voice hearers' are more likely to be victims of violence, rather than perpetrators and what voices say is often symbolic, not literal. As with suicide, people are safer if they are able to express and explore frightening thoughts. Groups can help to normalise, challenge and get control of violent voices, because the power of voices reduces when people share.

Talk about what group members have been doing lately; ask about life experiences, including conversations about bullying, alienation, loneliness and stigma. Strategies giving validation to important emotions, such as helpful and useful ways to express anger or grief, assist in finding alternative understandings of these scary voices. New and acceptable interpretations can bring the 'voice hearer' some relief. Should a participant raise issues regarding suicidality or increased distress, facilitators should be trained and supported to assist participants in finding appropriate extra supports and/or crisis services outside the group. Voices Vic provides resources, training and ongoing support for referrals where needed.

Endnotes

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{ *The Compassionate Friends Victoria:*
Peer support groups for bereaved parents,
siblings and grandparents }

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The Compassionate Friends Victoria: Peer support groups for bereaved parents, siblings and grandparents

Support groups form an integral, if not a defining, part of The Compassionate Friends Victoria's (TCF) service provision. As a Mutual Support Self Help (MSSH) agency, TCF has been providing state-wide specialist grief and bereavement peer support, to bereaved parents, siblings and grandparents following the death of a child at any age and from any cause since 1978. Support groups, along with other TCF services, are run by bereaved family members for bereaved family members. The organisation is also largely peer-governed and the primary evidence is "lived experience" and the delivery of peer support.

There is an emerging body of knowledge and research which reveals that, boosting and protecting social support, can increase an individual's capacity to deal with a potentially traumatic event. Presently, 26 TCF open-ended support groups operate throughout Victoria, and each has been established to help ensure that a peer support mechanism is available for the traumatically bereaved.

TCF Victoria's groups offer an opportunity for bereaved family members to connect with other bereaved individuals who are "*further down the track*", which, in turn, plays a vital role in normalising people's experiences of grief, fostering a sense of community and building resilience. Through the experience of mutual understanding and support comes the possibility of hope and, from that, the ability to reconnect meaningfully with the wider community.

We have confidence in our approach. TCF support groups follow the Standards and Guidelines researched and developed by Lifeline Australia (2009) which are continually being internally evaluated - formally and informally - by obtaining feedback from those who attend the groups.

Group members consistently report finding the meetings helpful, specifically emphasising the discovery of a community, of others outside the family, who understand and accept their complex and confused feelings and thoughts and who allow them the freedom to remember and speak openly about their children, even critically, in a safe, non-judgemental environment.

In this chapter, we wish to outline the dimensions that help ensure an optimum support group environment is provided for bereaved family members; we will discuss:

- the conceptual and experiential model that guides our group meeting ethos and format;

- the meeting guidelines and ethos that help ensure group democracy;

- examples of issues that can arise in groups and how they are managed;

- our training program for group leadership;

- and the ongoing management and leadership of groups.

Our Model

In 1951, Carl Rogers, author of *Client Centred Therapy*, stated his fundamental belief in the innate ability of people to determine their own growth (or regrowth following trauma). Rogers presented evidence, from his therapeutic experiences, that this fundamental self-determining process is best activated in a facilitative climate of empathic understanding, unconditional respect and similar openness on the part of the facilitating therapist. Later research supported and extended this to include all helpers and helping situations, including groups.

Our experience strongly supports the above. Consistently, we found that allowing the bereaved to tell their stories and to be listened to actively and empathically, without judgement, eventually helps them to regain autonomous control over their shattered lives. This does not preclude gentle challenging of inconsistencies or confusions or sharing our own similar (but significantly different) experiences. What it does tell us is that none of those intrusions from our world will be useful, until the bereaved person has walked around their story to the point where it is clear enough to feel in control and able to slot in outside offerings. Clearly, this will rarely occur in the first telling of their story.

Working within a Rogerian-based framework is challenging; it is not a passive process, as many have mistakenly thought, but requires active hard-nosed discipline to put our world aside and enter another person's world to help them clarify and confront painful feelings, confused thoughts and often obsolete patterns of coping. It also requires a firm belief in the effectiveness of this mode of working with people.

Values And Beliefs In Operation

Translating values and beliefs into guidelines for working with people has been a challenging and ongoing shaping process. These are guidelines we currently find valuable:

1. Bereaved people require clear, simple structures as they move from chaos to order. Resources are down and they seek security. Hence, our meetings are simply structured and always follow the same basic format.

2. In open-ended meetings, such as those at TCF, the newly bereaved get first priority. Hence, the major focus is on the opportunity to express their own feelings and thoughts and listen to the experiences of others. This helps to normalise their experiences. In those early days, rational strategy development is difficult and beyond most people. Expressing feelings has more healing value. In TCF groups, those who have been attending for some time probably gain most from the networks they have developed. To the newly bereaved they provide a model of hope and from their ranks come the next generation of leaders and support team members.

3. Promoting a non-judgemental atmosphere is vital; especially in the area of bereavement, where there can be self-blame and regret as well as anger commonly directed at one's self, one's family or friends, professionals and institutions. Balanced, realistic pictures of their world are best developed through non-judgemental listening.

4. Bereaved people need time to express their needs. Their story is painful and unique to them. We expect long pauses, hesitancy, messy thinking. In fact, we have found it

helpful to deliberately slow stories down – which also helps the listener.

5. In the very early survival days, it is OK to do some things for the newly bereaved (such as cook meals and mow lawns), but this should move quickly to doing things with them and not for them. Helping them regain autonomous control of their lives cannot start too soon.

6. Helpers naturally look for signs of recovery in those they are helping. But that should not be the helper's first focus. Rather, in this context, the helper's task is to establish an atmosphere of care and support, to focus on listening to and clarifying stories. Change and regrowth will then take care of itself.

7. Empathic involvement is demanding of a leader's personal resources. In our support groups, at least two caring qualified leaders/facilitators must be present.

8. Defusing and debriefing of leaders/helpers is imperative. Listening intensely to people with similar experiences to our own is not only draining, but inevitably taps into our own experiences and must be dealt with. The leadership team is checked at the close of meetings and we meet for a meal before each monthly meeting where the first focus is "How are WE?"

9. Finally, adopting a Rogerian approach means a caring empathic person is the primary criterion for leadership. Other important criteria include knowledge of the skills of helping, of the current understanding of the grief process and the ability to work in a team. We view leadership by a bereaved person down the track in their grief and a qualified leader as a gift. In line with early research by Carkhuff (1969) and others who came later, we believe it is better not to form a group rather than to have leaders without the above qualities. This is often misunderstood by well-meaning and keen volunteers (and professionals), but as Carkhuff found, "*helping can be for better or for worse.*"

The Three Part Meeting Format

The following is an outline of the format and organisation of a TCF support group; we believe a simple-structured program provides security for the bereaved. Also, meetings are regularly advertised and regularly held in the same comfortable, "neutral" venue each month. We have found that people often read notices and "*sit with them*" for a time, before finding the courage and energy to attend their first meeting. Finally, we believe it is best to have one person in charge of the overall support group operation and one person responsible for running each meeting; care of distressed people cannot be left to chance or confusion of roles.

The leadership team

The support group team currently consists of the coordinator and contact person in charge of overall operation and new contacts; at least one Support Facilitator responsible for general support and supporting the "helping process". All leaders are trained and, over time, modelling by leaders also means that each regular attendee becomes "*trained*" and better able to provide more effective support.

The Meeting Structure

1. **Informal welcome and cuppa for approximately 30 minutes**

This allows transition from the outside world to the support group world, pairing of new people and recording of personal details (although anonymity is a key component of our groups if desired).

2. **Formal sharing segment for a maximum of 2 hours**

Introductions

Following the welcome we focus the group with an appropriate poem or TCF's credo and outline some ground rules of which we suggest four: confidentiality; permission for the leaders to say "*we need to move on*"; recognition of energy needed to talk and therefore the importance of listening; people feel free to contribute as they feel able but to pass or be silent is also OK.

Input

Then a short input segment (bereaved people have short concentration spans) with three main goals – offer ideas and strategies, build hope and further help members settle into the group.

Sharing

The central part of the evening follows; this is the working part, where people share their stories and discuss the issues and problems they are facing. We systematically go around the group rather than let people come in indiscriminately, mainly for security and to ensure that everyone has an opportunity to speak.

Closure

Finally, we usually close the formal part by summarising the main points that have come out in the sharing, reinforcing networking and supporting each other, inviting them to stay for a cuppa and wind down and acknowledging the courage, especially of new members. We also always remind them that they may feel tired and flat over the next day or so, but stress that long-term benefits will be felt. We then close with a short poem or reading.

3. **Informal wind down and cuppa for around 30 minutes**

A vital time, when networks are established, unfinished business from the meeting is processed and support for those who are especially vulnerable is put in place. It also allows breathing space before re-entering the outside world. Finally, it incorporates time for defusing of the leadership team.

After meeting tasks

1. **Between meeting support for group members**

Each new member and all vulnerable members are contacted in the week following the meeting by a leadership team member. Sharing can have repercussions such as a "low" that lasts for several days, new tensions in relationships or the emergence of new issues as a result of the freeing experience of the group sharing,

2. **Debriefing the team**

There is an ongoing challenge to find time for this and it often relies on the caring networks formed within the leadership but it is vital for team

maintenance and leadership effectiveness; ideally it should be structured and focused.

Guidelines to Ensure Group Democracy

Below is a template (using actual words) to outline the "*ground rules for group meetings*" we suggest best reflect TCF's belief on how the optimum learning/growing support might be facilitated. We believe it reflects the qualities of empathy, respect and genuineness towards participants.

About our Sharing:

First let me emphasise:
Tonight is for you - to use as you feel able. Our task, as leaders, is to set up a supportive atmosphere, so you feel comfortable sharing your pain and in so doing, learn to better manage it. The opportunity is to share:

Where you are at this stage in your difficult journey to build a new life, and

Any issues you are faced with and would like to discuss.

Furthermore:
You may share as little or as much as you feel able to. Sharing or being silent – both are OK.

Feel free to contribute at your own pace.

Tears are OK - they show that you cared very much for your loved one and that you care for yourself.

And some of you may have some energy left over to cry with and show a little caring for others. But don't be too hard on yourself if your pain is still too great to go outside yourself and feel for others. It will come with time.

Five additional things from us; we call them "ground rules", but they are just reminders that help us support each other better, that keep us aware that our time tonight is limited, and that remind us about the best way to share and help each other.

1. **Firstly**, it takes courage to come here and to speak about ourselves. We ask that we **all listen when someone is speaking**, especially being aware when someone is just pausing and needs silence and time and space before continuing.

2. **Secondly**, we suggest that what we are most looking for in our struggle is just to be heard and understood. **Rarely do we need advice**. If we do, we usually ask directly for it. So be wary about jumping in with advice and suggestions.

3. **Thirdly, we are not here to rescue each other**, but to listen and to support each other to regain confidence in using our strengths. Distressing though it may be, we *need* to express and feel our pain. Unless we are "with" our pain, we cannot learn to walk beside it. So someone who is distressed and crying is actually doing something very positive. They are learning to handle their pain. Again, the best support we can give is to listen and encourage them to talk about their feelings and experiences.

4. **Fourthly**, I know our own needs are often very strong and we get wound up with the need to express and talk about them. However time is limited and so **we ask your permission for us to say "*we must move on*" if it becomes necessary. Is that OK?**

5. **Fifthly**, the issue of **confidentiality**. We ask you to keep what is shared tonight within the group. Some of us don't care who knows our story, but some of us are private people and will feel more comfortable and more confident

about sharing if we know that what we share will remain private in this group. Also we will inevitably be talking about other people who are not here (our children, family members, friends, professionals, etc.) and their privacy needs to be respected.

Issues that can arise during Group Meetings

It is essential that group leaders have a clear understanding of the above meeting guidelines, not only of the individual and group benefits they facilitate but also of the "*assertive power*" such knowledge provides in confidently running meetings. Based on feedback we frequently receive from group leaders, the running of group meetings is typically a smooth operation (particularly when leaders have opportunities to debrief following a meeting). The principal issue they face is the ability to be empathically attuned to each and every group member (a process supported by TCF's training in empathic listening and responding). To be empathically attuned while also ensuring meetings run on time and all participants are given an opportunity to speak can be challenging – and requires skill development and refinement.

Sometimes, however, additional group dynamics need to be addressed by group leaders; some issues can be as "simple" as keeping the subject on course, others can be more complex, such as managing a meeting so that the needs of newly bereaved group members and group members "*further down the track*" are equally attended to.

One of the most commonly reported issues is when a group member dominates the flow of group conversation. As we will discuss in the following section, "*Training and post-training support*", TCF's compulsory Lifeline-accredited group leader training provides comprehensive

group management strategies, including managing disruptive events. There are also post-training support programs provided by TCF that encourage reflection from group leaders in relation to best practice. A moderated email discussion group, for instance, allows group leaders to collectively examine a range of group-related issues – and discuss how they individually managed them.

We will use some contributions from group leaders in this online discussion group to help elucidate the common issues facing group leaders. To begin with, we will include an excerpt from a group leader, who reflects on the careful, respectful management of "*dominating*" group members:

> *When a group member dominates the conversation we try and pick up on a point [he/she is expressing] and ask the rest of the group to respond, or ask how they would handle it. Support leaders play an important role here as they can 'come in' on the conversation and assist in redirecting it. If it's something that occurs regularly, it's a good idea for the leaders in the planning/debriefing process to plan strategies to avoid the problem or at least to be aware of it. Another thing that I have found helps is emphasising the 'housekeeping' rules at the beginning of the meeting, that everyone needs time to share and get permission from the group to 'move on' if necessary.*

In the same online discussion, another group leader similarly emphasised the importance of guidelines, or house rules, as a mechanism for managing group dynamics.

> *I'm sure that most groups will encounter this problem from time to time. Often the dominating group member will interrupt to offer advice. Their intentions are good, but the*

manner unfortunate, because it does prevent the less confident members from continuing with their story once the flow has been lost. Like other group leaders, I also make a point of stressing the ground rules (gently) at each meeting. I have even printed them and put them in a small silver frame in the centre of the table. So far I have only addressed the group as a whole about this, deliberately not singling anyone out. Constant gentle reminders seem to be getting the message across.

As well as providing a safe environment, where everyone can equally contribute, TCF group meetings should also facilitate mutual support – peer-to-peer support – and within that support, the concept of hope. However, while it is essential that group members feel safe to speak openly of their grief experiences (and speak openly without fear of censure), a complex matter can emerge when a group member articulates to the group that his or her life "*has not gotten any better*" since the death of his or her loved one. How can hope be respectfully conveyed to the wider group without undermining the experience of individual group members? In another online discussion, a group leader reflected on her management strategies in these cases:

During my 10 years of leading the group, this problem cropped up a number of times, and on many occasions, I agonised over the fear that newer people would be put off by the extreme negativity of some people who were further along in their grief. I often used self-disclosure, first, to relate to the person expressing the negative thoughts, but then to make the point that things had very gradually changed for me, sometimes so slowly that it was only in looking back that I could see any progress – but change had happened despite me.

Follow-up phone calls certainly provided another opportunity to form a closer understanding and bond with the new person/ people and also gave me the chance to counter any very negative thoughts which had been expressed at the meeting.

Additionally, as a group leader relates below, within this issue is the "*juggling act*" of tending to the often divergent needs of newly bereaved group members and "*regular*" group members. To address this issue, this leader utilised a range of group management strategies, partially learned through TCF training programs, but also through accumulated experience as a group leader.

One difficulty is when those who are further down the track in their grief attend a group meeting precisely because they are going through a particularly difficult time and are feeling that life will never get better. When this sentiment is expressed, it is difficult not to look nervously toward the newly bereaved member. Is he/she thinking, "I can barely cope with life at the moment? What if I feel the same way five years later?"

It can sometimes feel like you are entering into a disagreement with the group member who is stating nothing will improve. But it is more a case of counter-point than disagreement. "Yes, we can find ourselves overwhelmed with our grief" you can say, hoping such counter-sentiment will also be heard by the new member. Or you can say, "I know I've had times where I've slipped back into the depths of grief and it's awful, but it's also so reassuring when you find yourself coming out of those spells." And it's worth emphasising that the support group is a great place for refuge in difficult times. By emphasising difficult times, the implication is that we also have "better times".

Still, in this sort of scenario, you may come to the end of the meeting feeling concerned that your counterpoint may not have been heard over the sentiment that "nothing improves". Bringing the meeting to a close with a good feeling is desirable. That's where summarising earlier points about hope can be helpful or having an inspiring reading or a poem.

Another group leader mentioned that if a newly bereaved individual was attending, he would immediately employ two discussion topics for the night: "*How we managed*" & "*How our grief changes over time*". The process of "*Introducing ourselves around the circle*" would still occur beforehand, but he would emphasise the need to address these topics. He felt that this was a beneficial approach to take, providing some level of reassurance to the newly bereaved, while also having the potential to reveal to less recently bereaved group members how their grief journey has developed.

Training and Post-Training Support

As the previous section shows, there are a number of complex issues that can emerge in a group meeting context that need to be handled confidently and assertively by group leaders. While a mutual support self-help agency such as TCF Victoria places "*the lived experience*" front and centre of their service provision, it is compulsory that their peer support volunteers receive training in the principles and skill set related to *Mutual Support Self Help*. For instance, TCF provides comprehensive training in empathic skills and self-care as well as group management, along with a working knowledge of the theoretical underpinnings of the organisation's charter.

TCF's training program – which operates on three levels – ensures that those who become volunteer

leaders will be able to provide a "duty of care" for group members and they themselves will receive ongoing organisational support.

Selection

The first focus is to ensure that group leadership is undertaken by sensitive and caring parents/ siblings/grandparents whose bereavement time span allows them to bring some objectivity to their support of others. The general TCF rule of thumb is at least two years post the death of their loved one.

Training

The second focus is to ensure that *all* those volunteering and accepted to lead a group are appropriately trained and thus able to provide consistently safe, knowledgeable and skilled support. Responsible duty of care must also include recognised training in effective leadership and TCF Victoria group leader training mirrors the internationally recognised training program researched and tested by Lifeline Australia (2009).

Post-training or ongoing support

This third focus of TCF's support group leadership program is vital. It recognises that because all TCF leaders are themselves bereaved, it is vital that well planned, ongoing and closely monitored support be provided for these volunteer leaders. Our ongoing outreach program is essentially a three year repeating program with a number of other support opportunities "*feeding into*" this basic structure.

1. Year 1: One-on-one meetings with group leaders (GL)

2. Year 2: Visits to & participation in actual group meetings

3. Year 3: Weekend GL Retreats

4. Other opportunities for sharing & discussion: Gathering program; GL Bulletin; Email discussions; Debriefing team; Informal contacts between GLs

One of the most important components of the outreach is providing forums for reflective practice and reinforcement of knowledge.

The Continuing Health of Support Groups

Along with post-training support, we wish to emphasise two further dimensions that help ensure the ongoing delivery of bereavement peer support meetings.

Succession

Succession leadership plays an integral role in the maintenance of support groups. Therefore, within TCF's training program, we strongly encourage current group leaders to keep a lookout for members in their group who show leadership potential (and who are also further along in their grief and therefore feel sufficiently able to support others).

TCF support groups now have a long history in the smooth handover of group leadership. Only rarely has a group needed to disband for a short period of time (i.e. when a current leader retires and some time passes before a group member takes up a leadership role); group leadership training being held on an annual basis helps facilitate a smooth handover.

Promotion:

Another dimension of group leadership is the ongoing promotion of groups within their communities. This is primarily achieved through activities such as: approaching local media to organise an article (or an ongoing notice) regarding the support group; leaders meeting with community organisations and explaining the function of group meetings; and distributing TCF materials to general practices, counselling services and community organisations (in particular, distributing pamphlets which outline the organisation's purpose, as well as the particular group's venue, meeting time, and contact details).

Conclusion

There are inherent challenges in leading bereavement support groups; issues can arise that require careful thought, action and reflection; in other words, leaders' responses must be driven by a "*duty of care*". We have found that having a strong guiding model for running support groups combined with a comprehensive training program and ongoing organisational support allows leaders to approach the emotional and intellectual demands of group meetings with both a sense of confidence and a sense they "*are not alone*" in their endeavours. The confidence and commitment of group leaders are integral factors in ensuring that the social and emotional benefits of TCF's peer support groups continue to be available to communities across Victoria.

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{ *The Borderlands co-operative:*
a place of inclusion and
co-production }

Jacques Boulet

The Borderlands co-operative: a place of inclusion and co-production

The historical and social context

The Borderlands Co-operative came about in 1997 – even if one could truthfully say that it was much longer in the 'making'. Indeed, it grew out of a deepening sense of frustration with - both – the established institutional processes of learning, working and living being imposed on people in (a society like) Australia and the palpable impotence of individual and organisational attempts at resisting that imposition.

As well, the demise of – literally – thousands of small local and issue-based community organisations and action groups during the nineties, in Victoria, precipitated by the election of an aggressively conservative government, contributed to the 'mood' of activists dropping from sombre to desperate. As usual in such circumstances, the neo-liberal and economic-rationalist 'divide and rule' strategy (masked as '*competitive tendering*', for example) employed by those in (economic and political) power worked its way into the hearts and souls of the diverse movements and the mere struggle for survival, by organisations and individuals alike, did the rest.

I had grown quite disenchanted with the ways universities were adapting to the neo-liberal expectation to commercialise, in order to cope with the systematic budget cuts and decided to leave tertiary education after about 27 year. In the several networks of which I was a part – ecology, community development and international solidarity – we often intensely discussed the 'where to now?' question and the idea of creating a place where community activists could meet, regroup and gather resources germinated... After a year of talking, thinking, finding resonance with lots of people, I invited the members of the networks to attend the launch of 'Borderlands' and become part of the creation of

> "… *a place where people can meet, talk, reflect, learn and teach, read and study, do 'cultured' things together, organise, administer and manage their networks or activities in and from, where consultation, consulting and counselling can happen, where a broad spectrum of basic resources are made available and accessible and which thus would become a 'node' of various intersecting local, national and international networks concerned about any, more or all of the issues discussed in more detail below. In short, a place where people can develop other ways of doing things together and have fun in the process of doing them*."
> (Boulet, 1997)

The *goals* of the to-be-evolved organisation were 'dreamt' to be necessary – if varied and multi-facetted - *responses to the need*

- … for a *profound re-development of our local communities.*

- … for *more ecologically sustainable local (suburban) living.*

- … for *international and inter-cultural learning, exchange and awareness.*

- … for *critical (self-)reflection and for active and participatory research.*

- … and for a *(re)new(ed) spirituality*, based on a newer-older understanding of 'spirit' as that

  "…which stitches the parts into the whole; … as that which connects; … acknowledging the ravages undue divisions of labour and 'expert' specialism have done and are doing to us and to the world… Borderlands should be about all-at-once."

The organisation (or the dream of it) was launched on the 21st of December 1997 (the last shopping Sunday before Christmas…), attended by about 100 people and a call was made to join and together develop both the **place** (which we had 'stumbled into' through 'connections' and was located above an underused church hall and consisted of two big former classrooms, one subdivided into three office-size sections); gather **resources** (we had started to bring together books and journals, furniture, stationary and were proud possessors of one antique laptop computer); and the **organisation itself**.

During the first months of 1998, we organised workshops, invited speakers and offered networks to hold their regular meetings in the premises and developed Borderlands' organisational framework, its vision and mission and its objectives, 'rules' and possible strategies to become sustainable. Various organisational formats – association, incorporated business, co-operative, for-profit or not-for-profit – were considered, but our early sympathies were and stayed with the *co-operative form*, especially in view of its historical origins and given that its philosophical foundations were felt to be in tune with the vision we had for Borderlands as an (ad)venture anyway.

So, what's so good about co-operatives anyway?

Whilst 'cooperation' has been around forever and is based on a solid core of social human attributes (even if some ideologues would like us to believe that humans are inherently self-centred, competitive, greedy and envious…), '**co-operatives**' have emerged as part of the resistance against the ravages of state-sponsored capitalism in the early 1800s. The '*Brotherly Weavers of Rochdale*' (Birchall, J. 1997) were part of a growing number of attempts at developing alternatives to the various dimensions of alienation experienced by growing masses of people – and of which the many 'utopian' communities in the (then) New World were another expression (as was Karl Marx and the various shadings of the socialist/communist movements he helped generate).

Through a co-operative, the Weavers wanted to avoid the double exploitation they suffered from the owners of the textile mills in the Manchester area; in addition to paying them hunger wages, the latter wanted their workers to buy their basic consumption goods in the factory shop at inflated prices – even paying them 'in kind' with their overpriced articles! The workers put some of their little savings together and bought 'bulk' from suppliers and producers and – from 1844 - sold the articles to the members of the first modern-age 'consumers' co-operative'!

Over time, co-operatives started to operate in the *financial* area (through credit unions), the *consumption* area (for consumptive goods, from houses to food), the *production* area (through workers collectively owning their company or other forms of co-operative production) and the *distributional* area (through co-operative transport

or the elimination of the 'middle-persons' between production and consumption).

The Weavers' co-operative principles still are basic to a – meanwhile – global movement with about 800 million participants; they have been re-formulated by the International Cooperative Alliance in 1995 (see http://www.ica.coop) and they are integrally taken over by the recent Australian Legislation of 2013. Very briefly, a co-operative is defined as an

> *'autonomous and voluntary association of persons with the goal of responding to common economic, social and cultural interests and needs by means of a collectively owned enterprise in which power is democratically exercised.' (transl. from Defourny, J., Simon, M. & Adam, S. 2002: 147)*

Co-operative values can be summarised as personal and mutual support and responsibility, democracy, equality, justice and solidarity and members espouse an ethic of honesty, transparency, social responsibility and altruism (ibid.). The Victorian Co-operatives Act (1996) requires co-operative members to abide by the following seven principles:

1. Voluntary and open membership

2. Democratic member Control

3. Member economic participation

4. Autonomy and independence

5. Education, training and information

6. Co-operation amongst co-operatives

7. Concern for the community.

As one can readily derive from the above, the co-operative philosophy approaches pretty closely that of community development in its various guises. But what about the *practice* of the co-operative movement? How have co-operative ideas and their realisations evolved since the mid-1800?

Co-operatives and the 'new social economy'

The ideas and practices of the co-operative movement have had their historical fluctuations and, especially during the last thirty years or so, have had to deal with the effects and impact of the latest phase in the globalisation of capitalism. Eschewing both state ownership and unfettered capitalism (and often misleadingly identified as the 'Third Way') the evolution of the co-operative movement has been located by Race Mathews (1999) within the context of the early Fabian and social christian/catholic philosophy of 'distributism', and re-emerging in Nova Scotia, Canada (Alexander, A. 1997) and in the co-operatives of Mondragon, Spain (Whyte W.F. and K.K. 1991).

Mathews also links the re-birth of the co-operative movement with some of the newly emerging 'alternative' political and economic discourses, notably social entrepreneurialism, social capital, associative and deliberative democracy, civil society and others (see also Hughes, V. 1997). He is timely in reminding us that the main goal of the 'distributist' philosophy inherent in cooperatives was and is the '*well-judged distribution of property*' (through the joint and personal ownership of jobs, capital, assets and benefits) and therewith providing support for the need to control and limit capital accumulation in (few) private, public or corporate hands.

According to Mathews (232), the co-operative movement has gradually adopted strategies

of 'scaling up' their operations and have lost touch with the principle of 'subsidiarity', the philosophical and practical cornerstone requiring *that members remain highly involved in the operations of their co-operative(s)*, rather then allow "*responsibilities [to gravitate] from those directly affected by them to others*", notably to 'executives' or to 'hired' personnel. Increasing size and decreasing transparency and sense of ownership of many credit unions and agricultural production co-operatives (adopting practices and processes of the 'big end' of town, in an attempt at remaining 'competitive') demonstrate their vulnerability to being assimilated into the processes and structures of the political-economy they came about to counteract.

The 'new' generation of co-operatives emerged in the wake of the movements of the late sixties and the crises in the capitalist world economy (and of capitalism as an ideology) of the early and mid-seventies. Simultaneously, the welfare state came under (renewed) attack, being partly 'blamed' for the crisis in capitalism as well as being a highly insufficient and stigmatising substitute for income security – let alone, offering a dignified livelihood for those needing it. Diverse attempts at regaining control over the personal and collective vagaries of the 'labour market' emerged through the establishment of local and worker-controlled 'employment initiatives' and work opportunities. Experimentation with the co-operative form also occurs in the context of 'developing' communities and, similar to those in the industrialised world, with various degrees of success and having to counteract ongoing attempts at assimilation into the capitalist political economies.

How has Borderlands tried to 'be' a co-operative?

Borderlands: example of an organisation that is based on the intrinsic understanding of 'community', i.e. from 'munus' (Lat.) or 'gift' and thus an assembly (i.e. the 'com' in community) of gift givers and gift receivers; surviving and being sustained on the basis of on-going processes of reciprocity in relationships between members, users, visitors (occasional birds of passage and those who 'hold' the place by their more on-going 'presence' (or presents) and who 'hold' the 'cooperative' potential of the organisation); a learning place for cooperation which also harbours other groups in cooperative exchanges of mutual benefit and of sustainable and transformative power.

I already mentioned that – from the beginning – Borderlands espoused an ideology of *sharing*; previously private books and journals found a place in a library of meanwhile well over 14,000 books; previously private furniture and equipment evolved into collective offices, kitchen and 'lounge' areas; joint projects started to 'happen' very early on and other small community-based groups were invited and came to share the premises and thus lessen the burden of rent and maintenance costs. But that was only the easy part....

Co-operative membership in Borderlands had been set at $100 per share or at an annual subscription rate of $25; after the first flurry of registrations, things slowed down and we now have an 'active' membership base of about 100 – many of whom forget to renew their subscription. Shareholders are meant to be 'active' in the co-operative, but

many are unable to contribute through activities and offer financial support only. Yet others find the fees too high and they do contribute through their participation in our projects or they help out otherwise. In sum, there's a core of about 25 to 35 people who are regularly present and 'do' things at and through Borderlands and another 50 or so who attend and participate in events or some of the activities taking place. The 'regulars' cover a wide variety of ages (concentrating around the 20-30 years and 50+ age groups), are overwhelmingly female and tend to live in a wide spread of suburbs around Borderlands' physical location, but with an increasing clustering in and around the City of Boroondara, in Melbourne's Inner East. We also have quite some 'birds of passage'; people come to rest for a while, after or during some often harrowing experiences in their previous work or personal life contexts, and then move on. Via newsletter, website, flyers and word of mouth, we are regularly approached and tell people 'what we're on about...' and some become involved, other stay a while and still other pick up the idea and try similar things elsewhere.

In sum, we're rather flexible and pragmatic about 'membership' and we tend to rejoice when we see the place being used and resources being put to work to achieve the ends of those who – like us – want to change the world a bit for the better, especially through the five areas in which we have chosen to become active and spend our personal and collective energies.

Borderlands also engages in *co-operative work-for-pay*; part of our 'founding' idea was to evolve other ways of 'valuing' work and of 'making a living', both to sustain the co-operative itself and to secure a personal income for those who would do the job. We were wary of joining the many and variously-sized organisations in the chase for the 'grants' dollar; we didn't like the strings attached to most of them and therefore decided to use the research, evaluation and consultancy skills and capacities of some of us (as well as the desire of others to learn these skills) and look for requests (by local governments, NGOs) to tender for commensurate projects. Many of us – after the disappointments with the 'bigness' of the institutions and agencies we had worked for and in – also hoped to avoid establishing ourselves as 'self-employed' individuals and – apart from the isolation it causes - making everyone else competitors. A slowly growing group of ex-academics and former students-on-placement have now joined and we are now about 12 who also use the co-operative to distribute the income we get for the work we do. Indeed, some of us are more capable of attracting jobs and projects whilst others still are at the beginning of this kind of work and thus join projects to apprentice themselves, but they still need an income. In some ways, we try to pay people on the basis of their *needs* rather than on the basis of the assumed intrinsic value of their work.

We are becoming more successful at obtaining – especially small to medium – projects and organisations now approach us to undertake project work for them. Whilst I certainly have felt the burden of being central to too many of such projects, gradually other worker-members are now very capably coordinating research and consultancy projects and providing leadership to others. Initially, three members with previous experience banded together to do a 'social impact' study for a Local Council and we have meanwhile completed well over twenty projects, involving five or six 'regulars' and at least ten other people on a more casual basis.

In addition to what I said about the 'distributive' practice at Borderlands, we try to experiment with mixing and matching (lowly!) paid work, voluntary work, 'apprentice' work (notably by the many students who have been on placement at Borderlands) and 'bartering' work. Indeed, early on we decided to establish a 'Local Energy (or Economic) Trading System (LETS)' which has had – at its peak – over 100 members and which is, after a slump caused by our moving premises and by the loss of some very active members, slowly gaining new momentum. Whilst I cannot go into detail (see Lietaer 2001 and Boyle 1999), LETS is equally one of the features of the newly evolving 'social economy', based on bartering between members of a local community and it is spreading rapidly on a world-wide scale. As with the co-operative, LETS intends to change working and living relationships between members of (local) communities and to help regain degrees of control over the means through which local people sustain themselves.

As to the financial survival of the Co-operative, we developed a loose formula, which leaves about 20% of the project 'income' to the co-operative and the rest is distributed amongst those who do the work and possible other project costs. We have received donations and we create sustaining 'overlaps' with other small organisations and capitalise on our joint resources. Rather than considering a specific 'niche' in which we are meant to belong and of which we are meant to be owners and 'experts', our holistic understanding of the task at hand for the alternative movement is that we need to be '*all over the place*' and affirm and celebrate the connections between the fragments into which those who govern us (have wanted to) relegate us. In that sense, we certainly attempt to fulfil the educational and community-building principles mentioned before as central to the co-operative idea.

Decision-making – in practice – occurs on three 'levels'; there are five elected Directors who, as usual, are responsible for the operations of the co-operative; we have, however, always invited anyone to come and attend meetings and members have done so. We have had four partial turn-overs of Directors, both indicating that there is willingness to become more responsibly involved in the operations of the co-operative as well as providing the necessary continuity. On another 'level', are the 'regulars' at Borderlands (either involved in projects, doing administrative work or being volunteers) who make day-to-day decisions as they become relevant given the 'flow' of activities. Finally, we use our quarterly newsletter and the website and the AGM reporting requirement as means to be transparent to all – even to those who are not 'technically' members. And yes, looking enviously at Maleny (Metcalf, 1995), we can improve on all of those...!

Conflict – in as far as it has occurred – has been dealt with informally; it is quite unavoidable for people, who have for much of their life been involved in competitive rather than co-operative work and living processes and contexts, to bring some of the fears and expectations and attitudes into an alternative environment. Many of the formal processes set up in the 'regular' economy and work settings can be identified as part of the problem we want to address and where possible alter. Whilst there is recognition that we need to comply with certain formal demands about workplace regulation and such, we are confident that our pragmatic approach – dealing with issues as they come – and the friendship and love we have for one another as well as our commonality

of purposes will carry us more safely than setting up a massive structure and rigid process aiming to cover all eventualities and vagaries of unfolding human relationships.

After seventeen years, the co-operative – in spite of a few anxious moments – has been able to pay its bills, to engage in wider awareness raising and to support all the other 'social change' activities we are interested in but for which there's no money available elsewhere (provided we would want it!). It has not always been easy; all of us have been crippled by socialisation and other working and living habits associated with the ideologies, structures and processes inherent in the 'system' we inhabit. But – and since this collection of chapters is about 'risk' – if we're not entering into to risk of *not* succeeding, *we will perish in the increasing certainty that our present ways of living and working spell disaster for us humans and for that which sustains us.*

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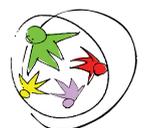Centre run entirely by people diagnosed with 'mental illness'

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