

Doing it together

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

www.ourconsumerplace.com.au



Doing it together... a collection of approaches, experiences and purposes of and in Groups, Committees, Organisations, Networks and Movements

Published by Our Community Pty Ltd Melbourne Victoria Australia

© Our Community Pty Ltd

This publication is copyright. Apart from any fair use as permitted under the Copyright Act 1968, no part may be produced by any process without permission from the publisher.

Requests and inquiries concerning reproduction should be addressed to:

Our Community PO Box 354 North Melbourne VIC 3051

Email: service@ourconsumerplace.com.au

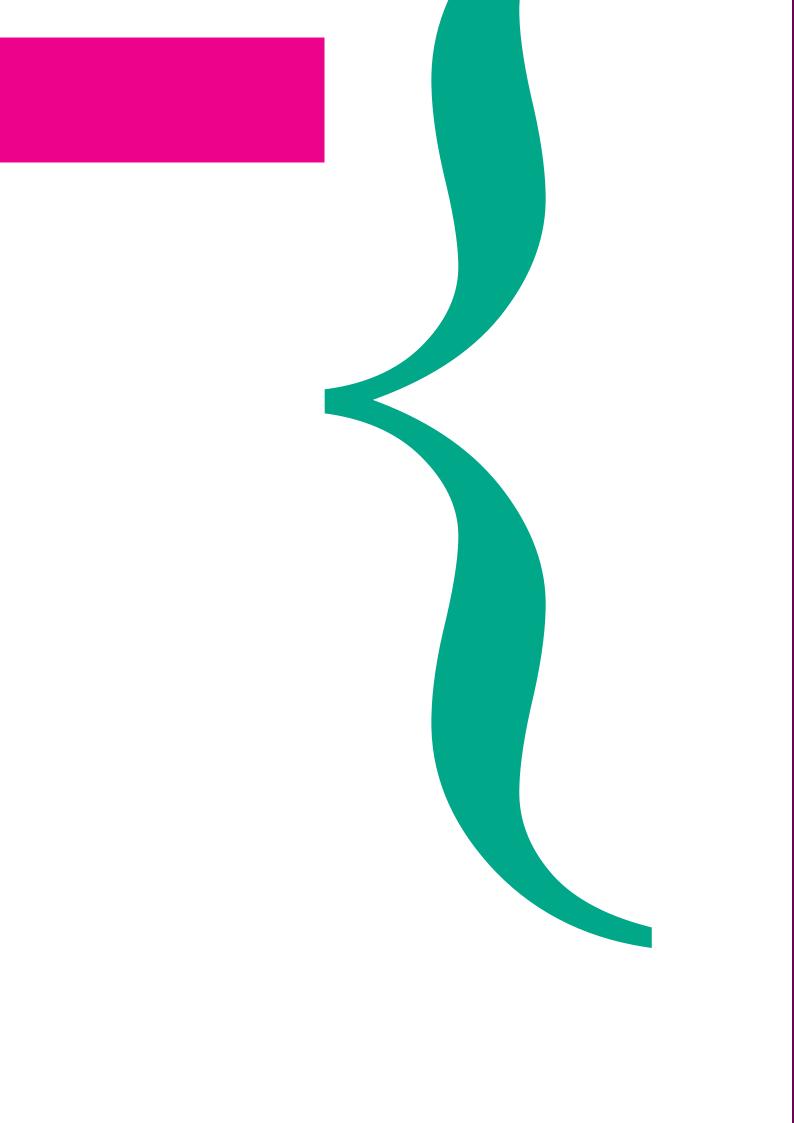
ISBN: 978-1-876976-55-2

Published: November 2015

Edited by Merinda Epstein and Jaques Boulet



a collection of approaches, experiences and purposes of and in



Contents

Introduction Merinda Epstein & Jacques Boulet	5
How to set up (Victorian) Consumer Advisory Groups (CAGs) - an Overview Merinda Epstein	17
Consulting with Groups of Consumers Merinda Epstein	27
How Consumers Can make the most of 'Time Limited Groups' Allan Pinches	36
Deakin Workshops: pioneering groups moving towards co-production Merinda Epstein	42
Deep Dialogue Groups Merinda Epstein	48
The case for Peer-Run Groups Liz Carr	57
How GROW works The Grow Group	64
The Maine Connection: an inclusive, volunteer, consumer community The Maine Connection	73
There are Therapy Groups and then there are groups Ann Tullgren	82
Working with therapeutic groups Fiona Mc Dermot	88
Facilitating 'Hearing Voices' Groups Voices Prahran Mission	97
The Compassionate Friends Victoria: Peer Support Groups for Bereaved Parents, Siblings and Grandparents Andrew Mc Ness et al	106
The Borderlands Cooperative as a welcoming, supportive, connected, inclusive and co-productive group/organisation and place lacques Boulet	115

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

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 socialrelational 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 deinstitutionalised 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 middleclass, 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.

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, he 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 diverse 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.

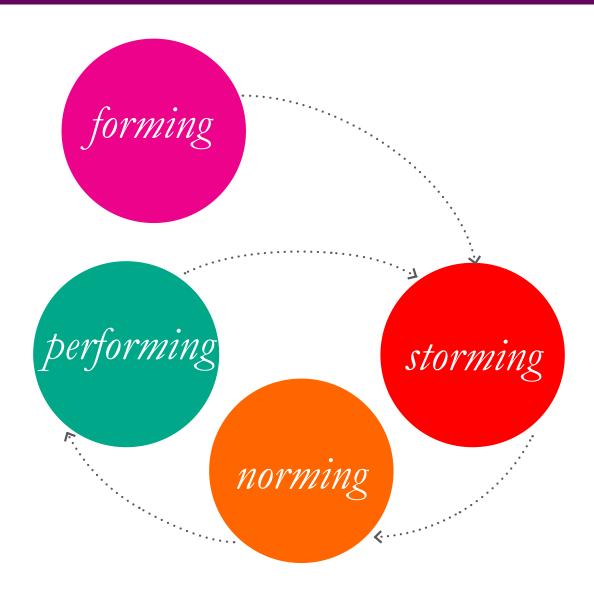
Each of these possibly benevolent outcomes, of course, (may) also have its downside... The education and learning groups offer might constrain and be oppressive for some members; groups can create and worsen interpersonal tensions; groups may exclude certain people and inter- and intra-group conflict 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



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 societyat-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 coproduction'. 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.