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

Merinda Epstein

This is one section reproduced from the book "Doing it Together. A collection of approaches, experiences and purposes of an in Groups, Committees, Organisations, Networks and Movements". A resource of www.ourconsumerplace.com.au

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*'[∃] 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 work¹² 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 internet¹³ 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. Research¹⁵ 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 In¹⁶

"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 Wadsworth¹⁷ 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 Dictionary¹⁸)

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 subgroup 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 agendd*', '*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 Pad²²

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 knowledge²³, 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 Window²⁴. 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 delivery²⁶, 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 crossfertilisation 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 proportionally²⁷.

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

Things consumers Things consumers know don't know Things services know things everyone knows enow and consumers don't things services Things services don't know k.now and *consumers* don't

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



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 peakbody 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 antioppressive 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

 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. <u>http://www.ourcommunity.com.au/files/OCP/</u> 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 PromotionFoundation, Melbourne

8. 'Supervisors' is a very difficult word for some consumers as it implies a hierarchy. Perhaps 'covisors' 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 <u>http://nursing.unimelb.edu.au/</u>
 <u>consumerinvolvementstation/keywords/co-</u>
 <u>production</u>

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 <u>http://www.ourcommunity.com.au/</u> files/OCP/MadMeetings.pdf

12. See Our Consumer Place book on Mad Meetings p.17 <u>http://www.ourcommunity.com.au/</u> files/OCP/MadMeetings.pdf *13*. See Interviews with consumer/survivor leaders at OCP <u>http://www.ourconsumerplace.</u> <u>com.au/consumer/resources#interviews</u> and "Deep Insight: Leaders in the International Mental Health Consumer/Survivor Movement share their thinking" <u>http://www.ourcommunity.com.au/files/</u> OCP/DeepInsight.pdf

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

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

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