# WELCOME TO OURCONSUMERPLACE.COM.AU

# RESOURCE CENTRE FOR MENTAL HEALTH CONSUMER DEVELOPED INITIATIVES

# THE STARTER KIT FOR CONSUMER DEVELOPED INITIATIVES



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# Welcome to Our Consumer Place

When we experience mental health problems, we may have to reclaim the confidence we have lost. Reclaiming power over our circumstances, living by our own decisions, having responsibility for our part in the community, and - for most of us - working, are all essential and life affirming. Our Consumer Place is designed to help people achieve those goals.

We welcome people who identify themselves as consumers, psychiatric survivors, ex-consumers, service users, and all other terms we use for ourselves. For ease of understanding we have chosen to use the word "Consumer" throughout this website.

#### What is Our Consumer Place?

We are a consumer-run mental health resource centre that offers information and advice to individuals and groups who are providing consumer developed initiatives (CDIs).

Our Consumer Place -

www.ourconsumerplace.com.au - has been developed by consumers for consumers - see our team of consumers working on the initiative. It is funded by the Department of Human Services (Government of Victoria) and auspiced by Our Community.

# What do we mean by Consumer Developed Initiatives (CDI)?

The possibilities are endless but the principle is the same: a consumer developed initiative is just a way to describe when we organise activities ourselves, whether to support each other, or to change society's perception of us.

We might start out getting together over a cup of coffee and hearing each other's stories. We laugh, we cry, we get angry together about things that need to change and we support each other to do all sorts of things that might not have been possible alone.

In order to achieve our goals we need knowledge and skills. Our Consumer Place is a place where we can meet, learn, and share with each other.

# What are some types of Consumer Developed Initiatives (CDI)?

We might want to organise ourselves into an advocacy group, a mutual support self-help group or a provider of support initiatives. We might decide to start a business to benefit all of us - maybe a plant nursery, café, courier company, or picture framing shop (these are all examples of what are called independent consumer developed initiatives, where consumers control all aspects).

Or, we might be part of a voice hearers' group led by a consumer and staff person, or we might run a support group and the organisation provides the meeting space (these are examples of a consumer developed initiative in partnership).

Or we might be a Consumer Consultant running a recovery group or a member of a Consumer Advisory Group (CAG) providing advice in a mental health service. (These are examples of providing a consumer developed initiatives as an employee).

We might be a volunteer for an organisation, where we support a peer on a regular basis, or we might be on a government committee, or we might provide a training session for mental health support staff, or at a school, or in the community.



### How can Our Consumer Place help our Consumer Developed Initiatives (CDI)?

Whatever your CDI's purpose, Our Consumer Place can help with achieving your goals.

Let's say you want to take the next steps to becoming an incorporated group. If you want to find a governance structure that will suit your group, learn how to run a meeting, pay your group's bills, balance the books, do your group's tax, manage boards, committees, staff and volunteers, use the media, attract funding, market your products, write reports, produce brochures, use new technologies...and more besides - then Our Consumer Place can help.

Our Consumer Place is adapting the resources from www.ourcommunity.com.au and will be developing powerful new ones.

#### **Current resources include:**

#### Starter Kit for CDIs

Help sheets in this section of the website provide information and advice about why you might want to be part of a consumer developed initiative, how to go about starting one up, and how to keep it going.

#### **Growing & Formalising Your CDI**

Help sheets in this section of the website provide information and advice how to go about taking your CDI to the next level. Here you will learn about becoming incorporated and developing your CDI's capacities in the areas of membership and recruitment, fundraising and financial management, governance, planning, partnerships, people management, marketing & media, using technology, and learning exchange.

#### Clearinghouse

This section of the website contains a

wealth of information written by people about consumer developed initiatives. There are sections for information from published journal articles, un-published articles, conference presentations, position papers, and opinion pieces.

#### Become a Member

Becoming a member of Our Consumer Place, Australia's leading resource for Mental Health Community Developed Initiatives, entitles you to receive an array of information and resources. This includes our regular newsletter, which keeps you up to date with the latest news and views.

Best of all, membership to Our Consumer Place is totally FREE.Membership is for individual consumers and consumer groups; organisations and staff that are in partnership with Consumer Developed Initiatives; and for anyone who is not yet involved in Consumer Developed Initiatives, but is interested in receiving information about these activities.

We will be offering our members many ways to be involved. Members can be involved in our online discussions, involved in the further development of our website, involved in developing our future Consumer Developed Initiatives training packages and training program, contributions to our newsletter, just to name a few.

#### Training/Events

This section of the website includes details about upcoming training, conferences, forums and other events suitable for people involved with consumer developed initiatives. The listing includes information about the events, who will be running the event, who is supporting or sponsoring the event, when and where the event will be held, and costs involved in attending.



#### **Directories**

This section contains a directory listing of consumer developed initiatives already in existence in Victoria, and information about how you can get your own initiative listed on the site.

A national and international listing is also included for those wishing to look a little further afield. This section fo the website also includes a listing of leaders who have experience in consumer developed initiatives and are willing to share their knowledge.

#### Message Board/Chat

We operate a message board service that members can post messages on. The posts can be viewed by all other members within the group, but these are not public message boards. Each posted message will be listed by the topic of the message, and will identify the senders First Name only, and the date the message was posted.

#### News & Updates

Find out the latest news in community development initiatives.

#### **Glossary of Terms**

Our glossary discusses why have we chosen the particular words that are used on this website, and what we mean by each particular term that we use.

#### **Contact Us**

We are developing an 'Agony Aunt' style section of our website to enable individuals or groups to contact Our Consumer Place via the internet to receive technical assistance and tailored information specific to their own situation and circumstances. Our Consumer Place also operates a phone assistance service, or you can drop into the office to talk about the needs of your group or get specific advice, information and assistance. All of our contact details are provided in this section of the website.





# Our Consumer Place Starter Kit

A Consumer Developed Initiative (CDI) is a broad phrase that describes anything purposeful that consumers do either on their own; or with a group; or in partnership with an agency; or as an employee or consultant.

The term takes in a wide variety of activities. The purpose might include starting up a walking group, putting on an event, getting politically active, or starting up a business, to take just a few examples.

These help sheets are designed to help you think about why you might want to be part of a CDI, how to go about starting one up, and how to keep it going. The starter kit includes the following Help Sheets:

- Introduction to CDI
- Joining a group
- Why do we want to start groups of our own?
- Forming a group
- Recruting members for new groups
- Membership of groups
- Group leadership
- Starting to keep records
- Communication between group members
- Advertising your group
- · Considering language and style

(If you have already started a group, and wish to become more formalised or get more specialist help in particular aspects of running your group, visit the Growing and Formalising Your CDI section of the Our Consumer Place website at

www.ourcommunity.com.au/consumer/ growingformalising

# An introduction to the idea of a Consumer Developed Initiative (CDI)

#### 1. Philosophy

The philosophy behind our commitment to Consumer Developed Initiatives: (CDIs) is primarily that people diagnosed with mental illness.

- can do things -plenty of things. To write
   off people with psychiatric disabilities
   as unfortunate, victims, incapable of
   learning new things, incapable of holding
   down paid work, or lacking in intellect,
   commitment or promise is to do them a
   great injustice
- achieve great things when they decide on the agenda and what they want to do and achieve in the world, and when their lives are not seen through a prism of illness or someone else's constant need to see them as fodder for therapeutic intervention
- can achieve more if they join together and work towards goals pre-determined by the group. Our emphasis is on groups rather than individuals
- like everyone else, have gaps in their understanding of important information. Some of us shudder at the thought of modern technology or how to write a submission or draft a report for a funding body. We know that for some consumers there are bigger gaps in our education either because of our experiences of episodic mental illness or society's reaction to it. Filling these gaps in education and skill can be a great thing to do if it is done competently and respectfully and driven by people who have had consumer experience.

#### 2. Principles

There are four primary principles that guide our commitment to CDIs:

• Mental health consumer groups, like

all other community groups and organisations, need resources if they are going to survive and thrive. At Our Consumer Place we do not provide money but we do provide guidance and resources which will help groups to find money if that's what they want

- We recognise that maintaining a group, particularly
  a group that is divided on central issues or under
  significant financial distress or has dwindling attendances
  and unevenly shared workloads, requires support that
  goes beyond the provision of written material no matter
  how comprehensive. We provide individual assistance
  to all mental health consumer groups through a variety
  of face-to-face, telephone and computer resources. We
  work with many experts at Our Community and we will
  make use of their resources.
- We are interactive. Our website has been designed to enable maximum participation from grassroots consumer groups and very experienced consumer organisations in Victoria. To the best of our ability we will respond quickly to the feedback we receive.
- Although our website is comprehensive and vital to the configuration of Our Consumer Place, it is not the only tool we provide as a resource centre. Our training and education arm is central to a gamut of capacity building opportunities, including meetings with individual groups to describe our website and how to get the most out of it, conferences, bringing groups together that have similar problems, and helping groups with research if this is needed.

# 3. Difference between a CDI and CDS and why we are using the term CDI

Originally we were funded to provide a resource centre for Consumer Delivered Services (CDS). Early on, we decided to change the title to Consumer Developed Initiatives. There were several reasons for doing this.

 The term Consumer Delivered Services (CDS) implied that the activity of consumer groups would (and perhaps should) be most obvious and active within the mental illness sector itself, either providing services in clinical and non-government settings or to consumers about issues to do with consumer consultancy, activism, systems change and so on. Although we recognised that this is one essential setting in the minds of many consumers who come together, we wanted our initiative to have greater scope.

- Consumer Delivered Services also implied a service-type structure for consumer groups and we were unhappy about this emphasis. We were not comfortable with the implication of a service structure with people at different levels of seniority, with tensions between paid and unpaid work and often responding to the agenda of organisations for whom the consumer services would be provided.
- Consumer Delivered Services seemed to us to imply that amongst consumers there were those who were the receivers of services and those who were the imparters of services. This is not how we wanted to promote Our Consumer Place. We are not running away from the reality that there are consumers who have become experts in certain areas of traditional consumer work such as advocacy, research, education, policy development etc., or that have special mental health/system experiences to impart; rather, we wanted to move towards a model that was about inclusion and knowledge sharing, mentoring and the provision of opportunities rather than services.
- Consumer Developed Initiatives (CDIs)
  also worked for us because the term
  'developed' felt inclusive (doing things
  together) and more respectful of the skills
  and knowledge and differing expertise
  of everyone a jointly-owned 'work in
  progress'.

#### 4. Scope

Initiatives can be tiny and they can be quite ambitious. We wanted CDIs to reflect this. Community Developed Initiative is a useful term because it widens the legitimate activity of groups. Our agenda for widening the scope is threefold:

- We wanted to include and encourage groups and sub-groups who want to meet around issues of great love as well as great sadness or great anger. We believe this is imperative. We want to support groups who are doing arty things, crafty things, singing things, sporting things, joyful and caring things for each other.
- We wanted to introduce the idea of reciprocity. That is, consumer groups supporting disadvantaged groups in their local community with a variety of initiatives, e.g:

- supporting another 'charity' and thus being the givers instead of the receivers,
- doing up bicycles for other consumers who don't have any transport.

The ideas are endless and reflect the fact that consumers are demanding inclusion in the local community rather than waiting for it to just happen. Consumers frequently talk about the empowerment of reciprocity. Few of us feel comfortable always being on the receiving end and the idea of diverse initiatives enables us to give voice to this idea.

• We also wanted to introduce the legitimacy of initiatives like fighting for important local or global issues that members feel strongly about. The group or a sub-group might want to fight for environmental issues, the rights of a local indigenous group, world poverty or keeping the local library in a rural town. These are all initiatives.

#### 5. Multi-interest initiatives

Groups don't need to be only one thing. For example:

A group that originally started out as a support group for people with a diagnosed mental illness might be interested in certain mental health issues as well as involved in other artistic, musical, political, civic or community concerns. This is the very essence if an initiative rather than a service. Nonetheless, there is no reason why one or several initiatives of the group might not be services of various kinds - servicing the community, the sector, local schools or the local library.

The final reason that we wanted to use the term Consumer Developed Initiatives is that it does not (as a Consumer Delivered Service does) imply that the activities that take place involve only people who use mental health services of one kind or another. Many might but others need to feel invited and included. This term allows for the inclusion of a diverse range of people, for example:

- More radical consumers (who often call themselves survivors) who would never use a traditional mental health service except under The Act when they have no legal choice;
- People who do not relate to the term 'mental illness' but still get something out of the group and want to stay engaged;
- People who use a variety of services that are not traditional mental health services. These would include various healers, counselling services, feminist practitioners, co-counselling, alternative medicine of various kinds and so on.
- People who have problems related to mental distress but who might have greater difficulty accessing traditional mental health support groups because 'mental illness' is sometimes not the reason for their 'groupness'. Here we include ex-prisoners, survivors of violent crime, survivors of domestic violence, survivors of childhood abuse, neglect and trauma, survivors of refugee camps and torture, etc. We believe that the idea of a Consumer Developed Initiative can be a multi-group event that brings the community together.

### Joining a Group

Joining a group might be something you are used to, and something you feel really comfortable about.

But for others it can be a bit daunting. It might have been a while since you've done something regular with other people.

The idea of joining a group might come about because you've heard about it from someone you know, or because a staff member thinks you might be interested, or because you've seen an ad in a newsletter, and think: 'That sounds interesting, I wonder if it's for me'.

We all have different reasons for joining groups, and we all have different expectations about what they will be like. That's why there will never be a shortage of new groups - as people figure out what's already there, and what doesn't exist yet.

Whether you're a stand-up poet looking for other consumers who read their poetry in public places, or you're a single mother looking for some mutual peer support, there will probably be a group out there for you, or at least other people who may be interested in joining with you to form one.

### What kind of group are you interested in?

There are lots of different consumer groups operating in Victoria. Most of them are small and informal. For this reason, it can be hard to locate them - they don't tend to have funds to advertise themselves so you're often most likely to hear about them through word of mouth.

The consumer groups that are associated with larger organisations are usually easier to find. For example, if you are involved with an accommodation service and the service also runs a peer support program, you are more likely to hear about the program

from other consumers or because the staff know about the program and can refer you.

That said, if you are not already involved with a related organisation, or your interests are outside of what they tend to offer, it can be difficult to know where to start.

Among the first steps, then, is to think about what you are interested in. Some other things to think about might be:

- Whether you are looking for a consumer-only group, or a broader group
- Whether you want to offer a group skills that you have, or to learn new skills, or a combination of both
- Whether you want to be involved in face-to-face meetings, or contribute in other ways.

#### Example:

You feel really strongly about the need to reduce community prejudice toward people with psychiatric disabilities - you would probably, therefore, be looking for a group that specialises in advocacy.

Is it important to you that the group works only on mental health issues? Or are you open to joining a group that has a broader outlook - for example, a disability group that is working on increasing employment opportunities for people with disabilities?

# Do you want to use the arts to make your message heard, or do you want to be involved in active campaigning?

Do you want to be part of an organised group and learn how they operate? Or do big groups put you off? Perhaps you would rather just meet up on a regular basis with a few people who are working on a particular project?

Finding a group

Once you have figured out what kind of group you are looking for, the next thing is to find it!

The CDI Directory lists many of the groups in your neighbourhood, what they do, where they meet, and what their purposes are. Keep in mind though that not all groups are well known or advertise themselves.

Another place to contact is the Victorian Mental Illness Awareness Council (VMIAC - go to www.vmiac.com.au, which is a group that provides support, advocacy and referrals to people who are experiencing or have experienced emotional or mental distress, as well as information and education about mental health services to consumers of mental health services and the wider community.

Also, check with any agencies or services you might be involved in to see if they know of any groups in your local area that would suit your interests.

#### Choosing a group

When you choose a group, there are a few things you might want to investigate before making up your mind.

If the group has a website, or has a brochure, look at:

- The values and aims of the group
- Are there any criteria to join, or is membership open to anyone?
- Do you have to pay any money to join?
- What days do they meet, how long are the meetings?
- Is there easy public transport access?
- Do both men and women attend?

If there's not enough information in the available material, you might want to email or phone the group or a representative, or visit first to ask some questions.

Alternatively, you might want to just go along to a meeting to see if it feels like a good fit for your needs.

#### Joining a group

If you are nervous about joining a group, remind yourself that probably everyone else in the group felt like that in the beginning.

A good test is to think about how welcoming it feels for you in the group. If it does not feel very welcoming, it's good to remember that this is not your responsibility. Any good group will have ways of welcoming new members. If this is not the case, then it might help you in making a decision about whether you'll come back or not.

Also, remember that it's OK to pull out of a group for any reason. You don't have to explain why if you don't want to. A good group will not ask this of you, they will respect your decision, although they might want to give you the opportunity to give them feedback in case there's anything that they can learn from your experience.

Another thing to remember is that you do have something to contribute to the group, even if to begin with you're unsure or nervous. You might not feel like saying too much when you first join a group - that's perfectly understandable.

You might even find yourself being interested in what only one or two people have to say, and find yourself wanting to get to know these people first. That's also OK.

It is important to reflect on whether the group you are interested in becoming involved with really is the right group for you. There's nothing worse than coming out of your shell to be involved in something, giving it your best shot, and then having a bad experience and going back into your shell.

If things don't feel quite right, it's not because there's something wrong with you, nor even that there's something necessarily wrong with the group. Remember that joining a group is about the 'match' between who you are and who the group is.

Sometimes it turns out that the group you've joined isn't really for you after all. Remember this is not about there being a problem with you - it's a problem about the fit between what you want and what the group is about.

# Why do we want to start groups of our own?

As people who have experienced 'mental illness', and the mental health system, we have a long and proud tradition of forming our own groups, whether these be leisure, support groups, service provision, or advocacy groups: there are some things you can't know unless you've been through them yourself.

It is this special knowledge that groups draw on and the members of the group share together. Often these experiences also provide the motivation for a group to form in the first place.

#### **Traditional groups**

Traditionally many groups and activities that we are involved in have been designed and structured by mental health workers out of some of their ideas about what will be of benefit for consumers. However, the therapeutic intent of these groups is often the reason some consumers say they don't get anything out of them. Many of these services would describe themselves as being 'client-centered', 'promoting empowerment' and 'for the benefit of consumers', but some questions to consider are:

- Do consumers decide the content of programs?
- Do they decide who leads the program?
- Do consumers have opportunities to run groups and activities?
- Are there consumers who are paid staff?
- Are there opportunities for consumers to learn new skills?

#### Consumer-developed groups

A lot of groups start because of the passion of an individual who wants to do something about what they have personally

experienced, wanting things to change so that other people don't have to have the same experiences.

When consumers decide to form their own groups, they are often looking to provide something that is not already out there. For example, many people have experienced what it's like to be feeling lonely and desperate during a long evening. A group might be set up to provide a way for people to share and manage those experiences - through an out-of-hours mutual support phone line, for example.

#### Example:

Karla tried to get help when she knew she needed it. But she didn't know where to start. It took her a couple of hours on the phone, trying to call her local council, the community health centre, waiting for people to call back, going through the phone book, before she finally found someone who could help. It made her annoyed and stressed to have to work so hard to find the help she needed.

A few days later, Karla realised that she had learned a lot about what was available in her local community and what was not. She now had a very useful bank of knowledge. She realised there must be other people in similar situations who needed this knowledge too.

Over the next few weeks, Karla talked to a handful of people who had had similar experiences of frustrated attempts to find help. They decided to meet up at Karla's house so people could share their knowledge about places you could go for help.

By the end of the meeting, they decided the purpose of their group was to create a basic directory of what useful services existed in their community, and to distribute it around their community.

The person who seeks to make changes on their own can become frustrated when they hit brick walls. A group can have greater influence. There is strength in numbers.

The group may spend its time together discussing the issues and deciding what actions need to be taken. Participants might decide how best to put their ideas and actions into practice. Finally, they may reflect and look at

what has worked and what didn't work, taking on an evaluative role as well.

All people have gathered valuable information and knowledge from their own experiences. Whenever people meet there is the opportunity to exchange this experiential knowledge.

#### Example:

Karl is sick and tired of people like him being described in the print media as "dangerous" and "violent". He has been writing letters to the newspaper each time they do a "crazed gunman" story, but he notices no change to the way the articles are written and his letters are never published.

His opinions have attracted a lot of support, however, from the staff and participants at the day program he attends. People begin to share stories about the impact prejudice has had on their lives. A small group starts to meet regularly, to figure out how they can best bring about a change to these stereotyped attitudes.

Another big reason for starting a group is for support. If the people involved in the group have had similar experiences, they know they will be understood, and know they will not be judged. Such groups are often described as mutual self-help or peer support groups.

Sometimes groups start because there is a smaller sub-group of consumers who feel that they want to share stories and activities with other people who make up this sub-group. These might be groups for young people; groups of people who share ethnicity; groups who are HIV positive; transgender groups; groups of people who identify as both consumers and mental health workers; and so on.

Often the more marginalised a sub-group is the more impetus there is to try and get together - initially perhaps to share stories around their experiences of being a minority, even within the broader consumer movement.

Other groups form for reasons of shared interests - a group of people who want to come down to the city together from a regional centre to go to the footy in the winter, for example, or a group of people keen to form a book club where they can talk about things other than mental health!

# The Purpose of a Consumer Developed Initiative (CDI)

The purpose of a CDI is to engage in activities and provide experiences that will benefit its members.

In mental health, CDI groups may have very different agendas. What does remain constant is that individual members need to decide what will and what won't be of benefit both to the group as a whole and to the individuals within the group. Towards this end, the group members decide the structure, focus, purpose and activities of the group.

### Forming a Group

This help sheet describes general categories of consumer groups:

- Local Groups
- Specific Issues/Interest Groups
- 'Illness' Specific Support Groups
- Short Term and/or Specific Purpose Groups
- Groups that Want Nothing to do with 'Mental Illness'

These are examples of the different types of groups consumers form as people come together to improve their quality of life and the quality of life of other consumers.

It's a useful list, but remember it is only a tool. In real life many groups take in aspects of some or all five categories and others change through time to become more like a different category of group. For example, a local art group might most of the time be a group that doesn't want anything to do with 'mental illness' but may include a sub-group that has met regularly to plan and host an arts event in Mental Health Week.

#### **Local Groups**

People who have common interests, experiences and goals benefit in a variety of ways from meeting with other people with a similar agenda.

Quite often they come together following their instincts that these other people have also been through a tough time. The meetings begin very informally and by mutual consent in places considered 'safe' by members of the group.

Many people want to be as far away from mental health services as possible and they want to have relationships with each other that are person-to-person and not patient-to-patient.

Slowly people start to realise there is a pattern to their meetings and that there is 'groupness' to the way they are relating to each other.

These sorts of spontaneous groups are often based around geographic locations where each member is familiar with a similar set of local issues.

#### Meeting places

Groups can meet in all sorts of places and ways - conversations in a coffee shop, a park, or in someone's own living room are often the starting point.

There are many local places that don't require payment. Local council offices sometimes have free meeting spaces for community groups; local libraries can also have free meeting spaces and the added benefit of computer access if the group needs it, plus other library resources that group members might want to access before or after the group meeting.

Some local neighbourhood houses have spaces where groups can meet, and many of these have the added benefit of having supervised children's play areas, enabling parents to attend meetings without the added cost of child care.

Access to local transport is another important consideration when the group is deciding where to meet.

Some groups want to meet away from mental health services or Psychiatric Disability Rehabilitation Services (PDRS). There are good reasons for doing this. Some consumers are wary of having their lives controlled or restricted by the fears of others. Many groups report that it is also about establishing themselves as an independent group that does not have to rely on the goodwill of services. (See Sylvia Caras - here - for a good discussion of these sorts of feelings.)

When you are freed from the feelings of being controlled or forever grateful there is space for groups to move forward with the agenda that is actually most important to them.

#### What are you going to talk about?

Initial discussions within a newly formed group may be free flowing, and may follow no particular agenda, purpose or expected outcome. No notes or records of discussions need to be kept.

In the initial stages groups may be 'informal' and come together naturally by word of mouth. The first six months or so will be a time of finding out about each other, what you want out of the group and whether people do really want to keep meeting, and if so why, where, when and how.

The discussions may begin by being focused on people's personal experiences relating to some particular aspect of their lives, and progress to discussions of what would be a better alternative.

People attending the group may talk to other people about these meetings. The original group members may wish to expand the membership by inviting more people to attend.

Attendance at the group is dependent on people's availability and the group makeup may change from meeting to meeting. People may attend for a period of time and then not attend, or may be regular attendees.

This is the same for any community group but in the area of mental health, groups need to take the real ups and downs of people's lives seriously in every aspect of the initial stages of planning the group.

#### Specific Issue/Interest Groups

Sometimes groups are formed between people with a shared interest such as a 'Line-Dancing Group', or over a specific issue such as a 'No Forced Treatment Group'.

Members might be drawn from local services, or they might come from all parts of Victoria, or from a particular cluster of suburbs or a particular regional centre. These groups can spin off from a local consumer group as people get talking and realise they share interests and/or ideas.

Sometimes these groups really need dynamic leadership during the formation stage and some perseverance and hard work to get them off the ground. They tend to be less casual in the way they attract members because they are coming together around an issue or interest that is already known. Some groups in this category rely heavily on a variety of advertising methods to 'get the word out'.

#### **Illness-Specific Support Groups**

For Illness-Specific Support Groups, participation comes about through self-identification with a specific 'illness'.

Some people come together because they want to know more about their 'illness', diagnosis, treatment and prognosis, others because they want to spend time with people who share similar experiences.

These groups sometimes appeal to people who have thought about the issues and find the 'medical model' acceptable.

Sometimes these groups are backed by wealthier non-consumer lobby groups and are therefore more resourced and more easily located, either on the internet or by phone.

Organisations that might be useful for people wanting to establish illness- specific groups include:

- SANE Australia http://www.sane.org
- Victorian Mental Illness Awareness Council - http://www.vmiac.com.au
- Mental Health Foundation of Australia http://www.mhfa.org.au
- Mental Illness Fellowship of Victoria http://www.mifellowship.org/
- National Network of Private Psychiatric Sector Consumers and Carers
- Eating Disorders Foundation of Victoria http://www.eatingdisorders.org.au/
- The Anxiety Disorders Association of Victoria http://www.adavic.org/ education/info/ocd.htm

Frequently people come together to hear from medical personnel and to have an opportunity to ask questions. If your aim is to attract such people the group may want to enlist the assistance of some of the above organisations.

Remember that there might be a group already established that is interested in your particular 'illness' or spectrum of 'illnesses'.

Even if this is a local group that is not in your area you might want to contact them and ask some basic questions such as:

- How did they get going?
- How did they find new members?
- How did they publicise their group?
- Were they financially supported by any other organisation/s and if so what were the pros and cons of this?
- Are they incorporated and what are the pros and cons of this?
- How often do they meet and what does a meeting usually consist of?

- Have they run campaigns or have they mostly been involved with getting 'expert knowledge' about their illness?
- What are the pitfalls of starting up a group?
- \* If the group has no money, how does it communicate with members?

It's important to know that Illness-Specific Support Groups don't have to be connected to a larger, overarching organisation. You might instead start by finding a space - a local library, community house, public health centre or someone's home - in which interested people can meet and determine what they would like to get out of the group.

### **Short Term and/or Specific Purpose Groups**

These groups have a different purpose than ongoing groups. They may be related to a larger project - such as finding out what a wider group of consumers thinks about a specific issue, writing parts of a report, or planning for a specific event.

Such groups usually won't 'emerge' in the same way as other groups, because they are formed around a task rather than gradually growing from one or two people. Some examples are:

#### 1. A sub-group of a larger CDI.

For example, the gay and lesbian members of a consumer organisation may seek a safe place to discuss issues specific to their sexuality with the intention of writing a policy for the organisation.

#### 2. A working group

For example, a consumer employee establishes a consumer group to help develop training modules for the organisation.

#### 3. A reference group

For example, a consumer researcher is investigating peer support models and establishes a consumer reference group to provide intensive commentary on all aspects of the research.

## **Groups that Want Nothing to do with** 'Mental Illness'

Many of those diagnosed with 'mental illness' meet other people diagnosed with 'mental illness' and become friends. This is partly because we are often drawn to people we almost subconsciously recognise as 'like us'.

If friendships are formed people often feel very relieved that they have actually found someone they can talk to who 'gets it', is non-judgmental, and who can talk about the darker side of 'mental illness' without freaking out.

Sometimes others with similar experiences join in too and a group may form.

These groups provide a place where people can truly be themselves, rather than putting on a 'well act' all the time.

It's important to note, however, that often the last thing people want in coming together is the formation of a 'mental health group'. People diagnosed with 'mental illness' have many other aspects to their lives - some are great at sport or singing, others are interested in parenting, or learning about food, or reading books.

Sometimes people just want to hang out with 'safe people' and do things totally unrelated to mental health.

These are often groups that ebb and flow as people do their own thing, but there is still a supportive 'groupness' that people associated with the group appreciate.

# Recruiting members for a new group

So you've got together with a few friends or colleagues, and now you want to set up an organised group.

Some thinking is needed before advertising for new members. Your little circle of friends first needs to get together to discuss the following questions.

- What's your mission?
- What would you like to grow from your ideas?
- What do your values need to be?
- Why do you need a new group? What's missing from the scene now?
- Do any existing groups reflect these same hopes and principles?

After thinking about these questions, the first place to start is with a bit of research.

## 1. Is there already a group out there that's doing what you want to do?

If so, are their practices, ethics and agendas near enough to yours for you to contemplate joining or partnering? Setting up a fresh group is almost always more work, and should be done only as a last resort. If there's anything that's close to what you want, use it.

There are various ways to locate other groups that may seem similar:

- Do an internet search. Searching the Our Community Directory of Organisations www.ourcommunity.com.au/directory is a good starting point.
- Contact the organisations mentioned in the Forming a Group help sheet.
- Ask local councils. They're usually very well plugged in to local networks.
- Talk to larger mental health lobby groups and see what they know;

- Speak to community development people in large not-for-profit organisations such as VCOSS or community groups that might not be specifically concerned with mental health such as Rotary.
- 2. Once you've investigated whether or not another group exists that's doing what you want to do, you need to:
- Check out in a bit more detail what you want. Throw ideas around together just to make sure that the visions people have in their heads match each other.
- Work out with each other what you want to tell people when you talk about your idea for a new group. Make it simple. Be modest and steer away from grand schemes. Don't feel you need to have decided everything in advance. It's better to wait until some new members have joined, because they will have ideas too.

#### Example:

#### **Group Name:** Insurance Group

What's the problem/idea/issue/need? People who have been labeled as having a mental illness are discriminated against in many insurance policies, especially travel insurance

What do we want to do about it? Mount a time-limited campaign

Who is eligible, how do we describe eligibility? Anyone who identifies as a consumer or mental health patient.

#### What are our basic principles?

- People who have been labeled as having a mental illness have a right to equal treatment in the provision of insurance;
- People who have been labeled as having a mental illness are the best fitted to say what the problems are in this area;

- Change can come out of well-organised community protest;
- You can mount a campaign with limited resources if you have the right skills and these can be learnt;
- Consumers can and must speak for themselves but they can also build useful political alliances;
- Personal experience and righteous anger can be a good selling point to the general public.

Once you've collected all the information you need, and talked through potential questions that people might ask you and decided how you'll respond to them, you can use the information you've collected to write an effective advertisement or story publicising your new group and its aims.

Many of the same principles apply to a general campaign or a single-issue group as apply to advertising a local neighbourhood group; however, word of mouth cannot so readily be counted on. Potential members will often be spread across a state or even nationally. Because of this, different strategies for advertising need to be thought about.

Remember that at this stage you're only looking for people to join your new group - nothing more than that. But in order to attract people with a similar interest you will need to have thought out and practiced a good selling line so that people can easily recognise your concerns.

#### Initial advertising

How you advertise your potential group depends on the following:

- 1. The purpose of your proposed group
- 2. Whether you have any money
- 3. Whether you have a core group of people who are willing to help
- 4. Whether your group is a local group or is likely to be geographically dispersed
- 5. Whether you're thinking of an diagnosisspecific group or not.

If the group is forming around very local service provision issues it's likely that you won't have to advertise much at all and word of mouth will be all that is needed. Otherwise, these are some useful ideas:

• Notices in shop windows;

- Notices in local clinical services, including acute units, and local disability support services;
- Getting a story in the local paper they're often hungry for personal interest stories;
- Notices in the local library.
- Community radio and community newspapers.

Look for specific services that overlap with your target groups. If, for example, the proposed purpose of the group is to create a drama club that welcomes and embraces people with all sorts of disabilities as well as those who don't have a disability then:

- \* Speak to all the disability services in your proposed geographic area, being very clear about what you want to create, and then posting advertisements;
- \* Speak to amateur theatre companies in your geographic area and ask them to suggest ways to advertise. Ask them if you can advertise on the back of their programs;
- \* Try neighborhood houses and other community groups.

#### Ongoing advertising

Some groups remain amazingly buoyant and, once established, need very little further advertising to bring new members in - word of mouth is sufficient.

However, because of the nature of people's experience of 'mental illness' the numbers in some groups will go up and down quite a lot.

Not only do the members of the group need to accommodate this fluctuation but there may also need to be further efforts to attract fresh members.

Important things to remember when advertising or getting your ideas into the public domain:

- \* The ad needs a catchy heading, otherwise people won't look at it
- \* Graphics help catch people's attention (they don't need to be posh)
- \* If you're handing out a flyer, you have to get your ideas on to one page only; it you're drafting an advertisement, into three or four paragraphs
- \* Put the most important things in the first short paragraph, because that's all some people read
- \* Make sure the important information is in there, easy to find, and easy to read including
  - Contact details
  - Meeting times
  - Venues
- Give information about public transport coverage to your venue and flag any opportunities to car pool
- Include a tear-off strip at the bottom of your posters with your phone number, email address and other relevant contact details.

# Membership of groups

Often in the initial stages of local group formation, issues of membership do not arise. It is simply assumed that people who want to join in do so because it is relevant to their lives and offers them something, and this is sufficient.

As the group gets a bit larger a range of issues can arise. If you do not start to think about these issues within the first six to eight months - ideally, before they actually emerge as an 'issue' for your group - then it is possible that something will crop up that may harm your group or cause distress to current or prospective participants.

There are a number of issues that need to be thought through by the group.

#### Identifying as a consumer

There can be political undertones that surround the question of 'who is a consumer', and it's wise to at least consider these issues when starting a Consumer Developed Initiative.

Differences may arise from the use in the field of psychiatry of diagnostic categories to group people into; or from the issue of mental health spending, where tensions may arise over the question of who gets the resources and who does not; or from the different ways that people understand and describe their own experience of distress, or their experience of using services.

The important thing for any broad-based group is to think about these issues and enter into discussions recognising that there can be quite profound differences of opinion.

The most usual (and arguably the best) way to organise membership of a Consumer Developed Initiative is to leave it open to all people who identify as a consumer, or a mental health patient, or as someone with a 'mental illness', or a psychiatric disability, (or indeed as a 'psychiatric survivor' or someone who is 'mad', 'batty' or 'crazy' - language that has been reclaimed by consumer activists). It is the process of the identification that is important.

The exception is when people come together around 'illness'-specific categories, where group members may think it is important for all members to be consumers in the strictest sense of the word. Again, though, it is the *identification* that is important. Nobody needs a medical certificate to join a consumer group thank goodness.

It is important to keep in mind the purpose of the group when considering issues of membership. For example, for groups that don't want to be active in the mental health field, or that want to position themselves as being open to the general community, issues of identification may be far less significant.

#### Welcoming new participants

There is still plenty of discrimination out there in the community. For people who have been active in the consumer movement for some time, there might be a degree of immunity to some of this discrimination, so it is important to remember that being involved in a group for the first time can be very scary. It's common for people to be unsure what to expect, to not know if what they have to say will be considered relevant, to not feel very confident.

That's why it is so important to develop some simple statements that encourage people to realise that they are welcome and that they will not be forced to do anything they do not want to do.

Equally, people need to feel that it will be easy for them to pull out of the group if they want, without feeling bad about it.

#### Open groups / closed groups

'Open groups' are most commonly seen as those groups that any member of the community can belong to. This might be very important if the group has a vision about breaking down prejudice and operates from the principle of not excluding anyone from the benefits of belonging.

The term 'open group' may also be used to describe a group that is not open to the broader community, but instead to anyone who identifies as experiencing 'mental illness'. Such groups can be very attractive to people who have themselves experienced exclusion and do not want to exclude others.

Bear in mind if you're considered setting up an open group that you may experience a particular set of issues. The group may have difficulty defining itself, setting its common purposes, deciding on topics of discussion, and deciding on priorities for group activities, or it may struggle with issues related to constant changes in membership makeup and attendances.

A 'closed group' is one that has restricted attendance or membership. The restrictions may be for some of the following reasons:

- Because it is an 'illness'-specific group
- Because it is a regional group
- Because it is attached to another service which has membership criteria
- Because members have a very specific set of values or activities they want to carry out
- To ensure that attendees have the same common interests / experiences / goals
- To ensure the safety of group members and that people feel 'free to speak'
- To ensure that group discussions are on topics specifically relevant to the group.

#### Examples of closed groups include:

- Women's only groups
- Men's only groups
- Parents' groups
- Tenants' groups
- Home owners' groups
- Residents' groups
- School parents' groups
- Groups formed around membership of a political party
- People who identify as 'Psychiatric Survivors'
- Older people's/younger people's groups.

A closed group might from time to time want to experiment with opening its doors (say, every six months) and become an open group for a particular period of time. This could see the group invite participation from the broader consumer movement, or the entire community.

Becoming an open group from time to time can be a great way to inform the wider community of your group's activities, and also to find out what is currently going on in the broader community.

It also provides a great opportunity for mutual learning exchange between the group and the broader community. Closed groups can still form useful partnerships on specific projects with other groups or organisations.

Some groups may be time-limited closed groups. Examples include specific project groups, where the group is closed for the duration of the project. This ensures continuity of group membership, without the group having to 'start again' every time a new member joins.

#### **Flexibility**

Groups need to be flexible to respond to changing membership needs over time.

A group may start off being open, but over time may shift to becoming a closed group.

Or certain activities of a closed group may become even more closed for a certain activity. An example of this would be where there is a closed group 'for renters within a local council area', but some of the activities may be specific to 'women renters in the local council area'. For the duration of the women-specific activities the group is closed to men, but after this it may be opened to 'men and women renters within a local council area' again.

#### Safety and privacy

You need to be careful about how you handle the private information that you hold about group members, and your own.

If you don't have an organisation or 'parent CDI' to fall back on, you need to think of some ways for people to contact your group without giving out anyone's home address or telephone number.

Some groups give out a mobile phone number but there can be problems with this. Firstly, the financial stress on the person charged with fielding the inquiries can become burdensome, and secondly, there are many people who live with 'mental illness' who don't have a mobile phone.

Email is another option, but it's not advisable to use the email address that has been provided along with your internet account. Instead, use a Gmail, Yahoo! or Hotmail address - they're easy to set up and free so you can have an email account especially for the group.

Remember, though, that you shouldn't rely solely on email because this will exclude many consumers. Not everyone is comfortable with using email.

Each group needs to weigh up the advantages of using a post office box number, mobile phone number or email address as a contact point for the group. It is likely that most new groups will decide on a mix of these, with responsibility spread across as many people as possible.

## Face-to-face groups are not for everyone

Not everyone is comfortable being part of or speaking within a face-to-face group.

Face-to-face meetings need not be the only mechanism for participation in a group. In fact the greater the range of ways to participate that a group can provide for members, the greater the potential for participation in the group.

#### Participation can be via:

- Face-to-face attendance at the group
- Writing ideas and opinions to contribute to the group
- Telephone or email contact with a group member who is comfortable in passing along the information gathered during the face-to-face group meeting
- Email communication to the group (if the individual has access to a computer and email and the group has access to computer and email).

### Participating in a group using electronic communication

Email lists and contact details need to be treated with the same diligence to privacy and consent as all other contact details and personal information.

Many people find they are excluded from joining debates and discussions and receiving information about group activities due to lack of electronic communication access. This is often a particular problem for older consumers who do not want to use computers or find this form of communication alien and scary. Others may be homeless or moving from host home to host home and unable to access internet. Others find the cost prohibitive.

On the other hand, many people find participation via electronic communication a 'safer' form of participation than face-to-face meetings. For some people with experiences of mental distress even leaving home to get the shopping is a daunting prospect. Many of these people experience community through their computers and without computer-based groups their lives would be very lonely.

Another thing to consider is that young people may be disadvantaged in groups where conventional post is the main, or even only, form of communication. Young people have been brought up in a computer culture. It has been part of their lives since they were very young and they don't 'get' other forms of communication and don't feel comfortable with more conventional methods. Email and texting via a mobile phone are often the only reliable ways to communicate with some young people.

Groups need to be mindful of all these issues when choosing their preferred communication options. The best solution is to provide a range of mechanisms, enabling group members to self-select their preferred method.

#### e-Groups

Many people with experience of 'mental illness' prefer to form groups through internet interaction. The three main types of internet-based groups are:

- 1. Discussion boards (also known as forums and bulletin boards)
- 2. Mailing lists
- 3. Chat rooms

It is probable that a group will exist that will be relevant to what you want to do and achieve. However, you do need some skills in navigating around the internet to make the most use of what is there.

If you wish to start an e-Group group yourself the easiest option is to use a hosting service with simple to use controls. Most hosting services display ads, but some will let you pay a fee to be free of them.

Check out hosting services such as http://groups.google.com.au or http://au.groups.yahoo.com/ and follow their instructions.

### Group Leadership

The idea of leadership is something that your group should think about.

Groups can come undone when what started out as an equal group becomes a battleground as people want to do different things or do them in a particular way. Remember that leadership doesn't have to be about one person calling all the shots. Leadership can be worked out amongst the group and revisited regularly as things change.

Leadership is important because if nobody takes any responsibility for the what, when, why, how and where, then the group will more than likely gradually dissolve. That's OK too - some things only have a limited life span, and fill a need at a particular place in time. But if you want your group to maintain itself, and even grow, then leadership is an issue that needs to be sorted out.

As much as anything, all members have the right to know how things will get done and who will do what, even if they are not interested in taking on any 'lead' role themselves.

#### Who is a leader?

There will probably always be both a fascination for, and a movement against the notion of leadership.

At the most basic level, a leader is someone who has responsibility for something. In the very early stages of a group, or initiative, somebody might have taken a 'lead role' in order to start the group and keep it going.

Everyone else may think of this person as the leader, but they may not see themselves that way. Or, they might think of themselves as the leader, but nobody else does. This is one reason why it is good for the group to have the leadership discussion - to be clear on this point.

It might be a deliberate feature of your group that nobody is a leader and everyone is equal. But even if this is the case, someone will still have to organise meetings or activities on behalf of the whole group, and someone will need to take responsibility for how group members communicate with each other.

Many consumers are uncomfortable about the notion of leadership and prefer other ways of organising themselves, or other words to use. This is understandable, because there may be serious concerns about power and powerlessness.

But leadership does not have to be about "Who has the power in our group?" It can instead mean, "How do things get done in our group?"

Here are some alternative styles you can consider for your own group:

- Facilitator: This describes more of an organising role. The facilitator might find the meeting place; host a meeting; take on the responsibility for the communication that will be necessary between members.
- Decision-Maker: This describes a leadership function
  where all main decisions are ultimately made by the
  'leader'. There may still be lengthy discussion, but the
  leader makes the final decision. This style is more rare in
  a Consumer Developed Initiative but might be used in a
  group that is involved in activities where some decisions
  have to be made quickly. It does not mean that all
  decisions have to be made this way for the entire life of
  the group.
- Collective Decision-Making: This is a process through which all main decisions are made by the whole group usually through discussion.
- Chair: This describes a role that can rapidly become a 'leadership' role, whether it is intended or not. If your group is 'meeting' based, the Chair is the person who guides the discussion and who has a clear understanding of what is to be achieved by the meeting.
- **Group Founder:** If the group is small and was started by one person, it is more likely others will regard this person as the 'leader' unless there is a deliberate discussion

about it. The group founder might want to be in a leadership position, or they might want to share around the decisions and tasks, and just be a member like everyone else.

#### What does a leader do?

Leadership can describe how things get done, but it can also describe qualities that people have. Leadership can mean being able to bring out the very best in other people, providing opportunities so that everyone is able to fulfill a valued and valuable role in the group.

You don't have to have one just person who fulfills the leadership role in your group. If everyone has a shared vision of what they want to do, and different skills to offer, each person's unique qualities are contributing to the leadership of the group.

However, the practical question remains: who does what?

A group that meets regularly requires that the following activities are done, so it's important to know who is doing what. The following activities might be done by one person, or by different people.

#### Organising a meeting

- Where will it be?
- If it is not in someone's home, who will locate & book the room and liaise with the venue?
- Who will host/chair/lead the meeting?
- Will someone take notes about what happened in the meeting and any decisions made?
- If there is an agenda for the meeting, who will write it, who will make sure that everyone has a chance to add something to it before the meeting?
- Who will communicate with other members to let them know when and where the next meeting is?

#### **Rotating Leadership**

Leadership of the group can be rotated around group members. This ensures that the work of leadership is evenly dispersed amongst all group members. However, this needs to be done in a respectful way and people should never be thrown in the 'deep end' when they have never taken a leadership role before. This is where 'mentoring' is such an important aspect of Consumer Developed Initiatives.

If the meetings are held in members' homes, then rotating the meetings amongst members and their homes can spread the workload. It is important that these possibilities are talked about as each new member joins the group.

However, an expectation that everyone will be comfortable with people coming into their home is unrealistic. It may be an unreasonable ordeal for some people.

It is important to respect the rights of people who want to belong to the group but don't want people in their homes. This is not just about sharing the workload; it is about respecting people's differing journeys. Remember too that there are people with insecure housing and people who are homeless. All these people need to be able to join in if they want to without feeling isolated or inadequate.

The group may wish to write a description of expectations of group membership so people will know whether they are expected to take a turn at leading the group, or hosting the group in their home, and whether these expectations are of all group members or by self-selection.

#### Example:

Quite often changes to the group's structure or operating processes may be driven from necessity.

For example, a group leader may have been comfortable with holding all meetings in their home, and all the group members were comfortable with this.

The group leader then shifts house and can no longer accommodate the meetings.

The group decides that meetings will be held on a rotational basis amongst members who are comfortable with hosting the meetings in their homes.

# Starting to keep records

Keeping records may not be relevant if you are primarily a social group, and indeed many groups deliberately do not want to have written records about any aspect of their group, often in order to protect the anonymity and privacy of members of a small group.

But if your group is getting larger, or you're having trouble keeping track of what happened last time you met, you may want to consider keeping some sort of record of group discussions or decisions made.

As your meetings start to take shape the group will need to think about and discuss:

- Who will take the notes?
- Who will write up the notes?
- Where will they be stored?
- Who will be allowed access to them?
- How is access gained?
- Will this be just one person's responsibility or will the task be rotated amongst the group members or a particular set of group members?
- What things do we want to record?
- What things do we not want to record?

All of these things need to be decided and put in writing by the group.

#### Your group's 'manifesto'

Once your group seems to be ticking along, you might want to consider writing down what the group is trying to do and what the group is starting to stand for.

One way to do this is for the group to brainstorm a modest list. It can sometimes help to think of it in terms of how the group would advertise itself - catchy heading, goals, processes, costs, meeting places and so on.

At this stage your group may be considered modest and to a large extent experimental. You may not know yet whether this structure is going to work. That's no reason though not to document what your group does. You can change your documentation as your group changes.

Once these lists are completed they can be made available for people who may want to join. However, they will be a 'work in progress' and people need to know that everyone can contribute to this ongoing self-definition of the group.

Later on, if your group decides, this kind of list can form the basis of a more formalised statement, like a mission statement.

Two examples of the sort of list you might produce are provided below:

#### **Riders with Style**

- 1. The group is open to all people who like riding bikes who identify has having experienced 'mental illness'.
- 2. We welcome new members but at this stage we only have a few spare pushbikes so members are encouraged to bring their own.
- 3. The group is committed to scavenging for bikes and gaining the skills needed to put bikes together and get them ready for the road.
- 4. The group will meet once a month in the Babylon Community Complex 25 Moore Street, Babylon 3333.
- 5. To start with we are hoping to organise group rides once a month.
- 6. The only costs will be if we need to catch a train to our starting point (or catch an ambulance back).
- 7. This group is wholly consumer developed and run.
- 8. Riders with Style has nothing whatsoever to do with therapy. If we get fit as a consequence of having fun, seeing new places and enjoying each other's company then that's a bonus.
- 9. All these guidelines are new and are being trialled. They will be regularly reviewed.
- 10. For more information either phone 9999 9999 or email riderswithstyle@riders.org.au

#### **Out or In Women**

- 1. The group is open to all women with a 'mental illness' who identify as lesbian.
- 2. We welcome new members and are committed to making all women welcome.
- 3. The group will meet once a month in members' houses and we will rotate hosting duties, but there is an opt-out option for people who can not or do not wish to host meetings in their homes.
- 4. Women are free to be as open or 'out' as they feel comfortable with, both in relation to their sexuality and 'mental illness'.
- 5. If anyone else's language upsets a member we will stop and talk about it. Members are encouraged to make the group aware if they are feeling uncomfortable.
- 6. The group will not have a budget nor be dependent on any other organisation for financial support.
- 7. The group is committed to improving the lives of its members and all lesbians who identify as having been labeled 'mad' or diagnosed with a 'mental illness'.
- 8. All these guidelines are new and are being trialled. They will be regularly reviewed.
- 9. For more information either phone 9999 9999 or email outorinwomen@outorin. org.au ■

# Communication between group members

Regular contact and two-way information exchange between the group and its members is important for maintaining the existence of the group.

#### Informal two-way exchange

For small groups an easy way to inform all group members (those that attend meetings and those that are unable to attend) of the group's activities, actions, plans, discussions and decisions is to issue a regular bulletin.

Bulletins can be used to let a wider group of interested people know what your group has been up to, and can also provide an easy way to regularly communicate between group members.

A double-sided, hand-written A4 piece of paper, or a short electronic version, is all you need (in fact shorter is often preferable to longer).

You might produce two versions of your bulletins, one for just group members, and one that is written for a wider audience, as there may be some information that's appropriate for members' eyes only.

Bulletins can be easily turned into a twoway mutual learning exchange. For example, you might invite group members to write a short opinion piece, discussion paper, or idea, which can be sent out with the bulletin to all group members, or included within the bulletin.

Editorial policy is an important consideration for your group, particularly if you are inviting contributions. For example, if people are being asked for their opinion they need to know that what they provide will not be edited without their permission. They shouldn't, though, expect that everything they provide will always be printed.

There may be very good reasons for leaving some things out - there may be space or legal considerations, for example.

There does need to be some rules. These need to be developed by the group but might include things like:

- No naming and shaming of individual people;
- No criticism of other group members;
- Steering clear of anything that may bring the group trouble legally.

#### **Rotating writing**

Another option for encouraging mutual learning within a bulletin is to rotate the writing amongst group members.

For example, a specific section of each edition of the bulletin could be left for the writer to have their say about any topic they see as relevant.

Other content of your bulletin can include:

- A summary of what went on during the last group meeting;
- A summary of items of interest that have appeared in the media
- News relating to the group or individual members (with their permission)
- When and where the next meeting will be held and what will be discussed or decided there.

#### The bulletin as history

Cumulatively a 12-month collection of monthly bulletins provides an easy record of annual activities, and can serve as an 'annual report' of the group's discussions, decisions, activities and achievements.

Monthly bulletins supply information without being too onerous to produce or too onerous to read.

They also ensure the group maintains regular and predictable contact with members. This is especially important for group members who may not be able to attend meetings but wish to be kept informed of what has been discussed / decided within meetings.

Monthly bulletins don't need to be beautifully designed and professionally printed; in fact, there are advantages if they are not. A simple bulletin that can be photocopied or forwarded on as an email will allow group members to show a friend or other interested parties, who may then request their own copy.

#### **Costs of communication**

There is no doubt that good communication between members is essential for a group to survive, however in a small group this is often the largest cost item.

The inherent costs involved in using 'snail-mail' (the post) as a method of communication with members can be daunting.

Costs for stationary, printing / photocopying, envelops and stamps can all add up to substantial amounts during the year, especially if the group membership is large or if bulky newsletters are being mailed to members.

With the explosion of electronic communication systems, many groups have become more reliant (and in some cases solely reliant) on email as the primary method of communicating with group members.

However, you shouldn't let the lack of computer equipment, computer literacy or knowledge about keeping databases stop you from maintaining contact and continuing the communication exchange between the group and its members.

It is still possible to keep a simple paperbased list of group members' names and contact details (mailing addresses, phone numbers and email addresses) and keep in touch without using email, or by using a combination of email, snail-mail and face-toface methods of communication.

Group members will probably want to be notified of upcoming meetings and any changes to the meeting time/date/place. They may also consent to other information being received from the group (newsletters from other similar groups, information about relevant forums they may wish to participate in, etc.).

The group members need to decide who will be the contact person to receive this information and who will be responsible for sending it on to individual group members who have consented to receiving it. ■

# Advertising your group

his help sheet is designed to help you think about the different ways that you can advertise the existence of your group and attract new members. It covers:

- Bulletins
- Making a brochure
- Newsletters
- "Expression of Interest" forms
- Membership forms

#### **Bulletins**

Bulletins provide a low-fuss way of communicating with and between group members. But they can also provide a way to regularly communicate to people who are interested in your group but who maybe don't want to (or can't) attend face-to-face meetings, or aren't ready to join the group yet.

For small groups a bulletin is an easy way to let the broader community know about the group's activities, actions, plans, discussions and decisions.

They don't need to be fancy. A photocopied hand-written A4 piece of paper functions just as well as any other.

Bulletins can also be sent electronically to people who have indicated their interest in your group and are comfortable with email.

And if your group already communicates internally through the use of bulletins, then it is a fairly simple matter to edit out anything that is sensitive, private, or not relevant to anyone else but the group, and send it out to the broader community.

#### Making a brochure

The group may wish to advertise its existence to the broader community and a brochure can be a successful way to do this.

Your group can also use a brochure to attract new members. Before you start writing your brochure, it might be useful to consider the following points:

- What do you need to say in the brochure? Try not to get too bogged down in lots of words. Stick to the main points.
- Who is it written for? It's important that this point is clear to you as the writer of the brochure and to the person who picks it up.
- How do you want the brochure to look Glossy? Flashy? Professional? Simple? Welcoming? Who will design it? Can you afford to get it printed?
- Where will you distribute it? How will you know if the supply has run out? Who will be responsible for supplying more?

The answer to these questions will depend on the purpose of the brochure. If it is mainly to attract new members to your group, there are a variety of ways you can go.

#### Brochures as two-way communication

In this type of brochure, information is given about the group, and information is sought by the group from the broader community.

The information given by the group may include:

- Name of the group
- Type of common interest / experiences / goals of the group
- Purpose of the group
- Type of group (open or closed membership)
- Meeting times and places of the group
- How to contact the group.

The information sought by the group may include:

- Topics or issues of concern from a community
- Ideas for priorities of discussion by the group
- Expressions of interest from individuals who would like to join the group (and their contact details)

 Feedback from individuals who would like to receive more information about the group and its activities (and their contact details)

Two-way information brochures are a good way for your group to start interacting with the community.

#### **Newsletters**

Newsletters are a good way of reaching a wider audience. They can include articles, opinions, reports of current debates, news, events, quotes, cartoons, photos, etc.

People can also be invited to submit their poetry, jokes, essays, thoughts, ideas, and art.

Like your bulletins and brochures, your newsletters don't have to be flashy to be effective.

'Expression of Interest' forms

Expression of interest forms - forms that people can fill in if they're interested in taking part in or finding out more about the group - can be included as part of or alongside your brochure, bulletin or newsletter.

Expression of interest forms have an additional function for the group if they ask 'How would you like to participate?' The group can then endeavour to meet the needs of individuals by ensuring there is a range of ways people can participate.

Examples of different methods of participation include:

- Face-to-face attendance
- Writing ideas and opinions to contribute to the group
- Telephone or email contact with a group member who is comfortable in passing along the information gathered during the face-to-face meeting
- Email communication with the group (if the individual has access to computer and email and the group has access to computer and email)

#### Membership forms

Membership forms can also be included as part of or alongside your brochure, bulletin or newsletter.

Membership forms should include some very brief information about the group - where and when it meets, who is eligible to take part and the methods of participation that are possible, for example - and should also provide a space for

- the person's name
- their preferred method of communication (phone, email or mail)
- their interests (optional).

You must also include details of how the membership form can be returned to the group - i.e. where to post, fax or email it to, and whether it can be hand delivered.

#### Issues of privacy

Any time that a group asks people for personal details, such as phone numbers or mail/email addresses, it is important that it is made clear what the information will be used for and who will have access to it.

It is also extremely important to be clear that people's personal details will not be used for any other purposes or passed on to any other people or groups.

People have a right to have their privacy protected, and this is both a moral responsibility and a legal requirement for all groups.

Privacy information should be included as part of the membership application form and the expression of interest form.

#### Thinking Point:

An important question for each new group to discuss in relation to principles and privacy is; 'Does completing the membership form force a person to disclose their consumer or other status?'

There is no right or wrong answer to this very important question. In fact, there are very good arguments for both asking people to disclose and not doing so.

Each group needs to weigh up the pros and cons and come to a conclusion that they can live with and argue for if they are challenged in the future.

# Considering language and style

The most successful brochures, bulletins and newsletters are written in the groups' own language (all small groups of people have their own specific and well-understood dialect) and developed and designed by the group members.

Font, format, colour, inclusion of logos, photos and graphics, and the style of printing are all group decisions.

However, this can become a bit more of a challenge when the document is being designed for a consumer community that is:

#### 1. Dispersed geographically

for example, a group that has members in very different parts of Victoria from the inner-city to country towns;

#### 2. Dispersed culturally

# 3. Dispersed socio-economically sometimes there can be a huge difference in how much money people have; and

## **4. Dispersed linguistically** (the language people speak at home).

Despite these differences in backgrounds and experience it is amazing how often consumers from all over Victoria with very different (on the surface) experiences can "finish off each others' sentences" - that is, laugh at the same jokes, and speak the same "language" when it comes to experiences and outlooks.

Nonetheless, there are big differences in the ways people live and use language and these must be thought through when you're designing your communications.

For example, reaching different ethnic communities may seem very difficult, given

the expense and dire shortage of interpreters, but you might be able to think laterally about who you know and who might want to help you.

#### The importance of language

If you would like your group to include and be welcoming to consumers who use private psychiatric services there is a big chance that they may not have heard of the word 'consumer' used in the way the consumer movement uses it; let alone words such as 'nutcase', 'batty' and 'loony' that have been reclaimed by activists.

They might be much more familiar and comfortable with the word 'patient' than 'consumer', and may well be offended by the use of words they have come to associate with abuse or derision.

At the same time, many consumer movement activists might well be incensed by the very term 'mental illness'. They may refuse to use it at all.

In groups that have to cover a broad spectrum of experiences there will be a need to accommodate both points of view. In these circumstances language becomes extremely important and can never be taken for granted.

#### A question of purpose

For many groups language isn't such a problem because what they want to do has nothing to do with mental illness services of any kind - these groups, thankfully, can just be people. A quilting group or pool playing group, for example, probably wouldn't need to grapple with these language challenges - they'd just need to know how to sew or hold a cue.

It is clearly harder to bring together a group which has amongst its objectives a critique of mental health service provision. However, it is not impossible.

One way of attempting to deal with the issue of language is to suggest a trade off, whereby people are prepared to compromise on the language used in a brochure on the proviso that the brochure includes an outline of the language dilemma and explains why the group has chosen the words it has.

Whatever you decide, it will be interesting for your group to explore these differences in language and to discover that what lies hidden behind the divergence.

#### Style and printing

Brochures, bulletins and newsletters don't need to be expensive to produce, they don't need to be glossy, and they don't need to contain lots of fancy pictures.

Quite often, in fact, brochures, bulletins and newsletters will need to be photocopied so the simpler they are the easier they will be to reproduce.

Photocopying is also cheaper, and an added bonus is that a lot of smaller agencies that may stock your brochure in their information holders or pamphlet racks will be quite willing to replenish stocks themselves if they are able to be photocopied.

Having a simple, easy-to-photocopy design will also help in the dispersal of your brochures, bulletins and newsletters from one group member to another, and from group members to others who may show an interest. This means all group members can help contribute to the advertising and recruitment of members for the group.



# Become a Member

Becoming a member of www.ourconsumerplace.com.au, Australia's leading resource for Mental Health Community Developed Initiatives, entitles you to receive an array of information and resources.

Membership includes our regular newsletter, which keeps you up to date with the latest news and views.

Best of all, membership to Our Consumer Place is totally FREE.

Membership is for individual consumers and consumer groups; organisations and staff that are in partnership with Consumer Developed Initiatives; and for anyone who is not yet involved in Consumer Developed Initiatives, but is interested in receiving information about these activities.

We will be offering our members many ways to be involved. Members can be involved in our online discussions, involved in the further development of our website, involved in developing our future Consumer Developed Initiatives training packages and training program, contributions to our newsletter, just to name a few.

To Become a Member, visit:

http://www.ourcommunity.com.au/consumer/becomeamember

# About Us

We are a consumer-run mental health resource centre that offers information and advice to individuals and groups in who are providing consumer developed initiatives (CDIs). Our Consumer Place -

www.ourconsumerplace.com.au has been developed by consumers for
consumers. It is funded by the Department
of Human Services (Government of Victoria)
- www.dhs.vic.gov.au and auspiced by Our
Community - www.ourcommunity.com.au.

The funding to establish and provide this service in Victoria, makes it a first in Australia, with examples of similar and proven services in Europe and the United States.

Our Consumer Place welcomes input and requests for information/assistance about any aspect of forming, running or dissolving a consumer developed initiative. Please see our contact details on the back page.



#### Merinda Epstein

A cartoonist, writer, teacher, learner, chronicler, historian and activist, Merinda has lived, fought and taught her way through 22 years of active service for people diagnosed with 'mental illness' in Australia. Merinda believes Our Consumer Place provides an ideal hub for intergenerational change, mentoring, the preservation of the history of activism, and the provision of a smorgasbord of skills, knowledge, information, training and technical support for all groups of people connected through their experience of madness, badness and sadness.

A co-winner of the 2004 Australian Human Rights Award in the Community Category, Merinda holds a deep belief that it is time for 'consumers' to develop their own ways of doing things - their own groups, their own services, their own networks, websites and small business. She believes that with unity and respect for each other, and a rigorous understanding of what groups need to know to function well, we can achieve much more together - in our own groups and human rights troupes - than we can as individual atolls in the sea of pretty tough politics that surrounds mental health service provision in this country.



#### Jon Kroschel

Jon Kroschel is Melbourne based and has been pro-active in the Australian Mental Health Consumer movement for over 20 years. Jon is the Consumer Consultant for Alfred Psychiatry, the Director of Participatory Action Research (PAR) at Alfred Psychiatry Research Centre, a Director on the Board of Directors of the Quality Improvement Council of Australia and New Zealand (QIC) and a member of the International Initiative for Mental Health Leadership (IIMHL).

Jon has received many awards for his work. His field of expertise lies in innovative project development and evaluation in mental health and consumer settings.



#### **Cath Roper**

Cath calls herself a survivor (of involuntary mental health service use). She became a teacher, then a mental health consumer consultant and more recently, a consumer academic at the Centre for Psychiatric Nursing.

She teaches post graduate mental health nurses at the University of Melbourne and is involved with research and education. Although definitely mad, she believes consumers should have opportunities to shape their own lives, with the same rights and privileges as all members of our community.

### **FEEDBACK**

Our Consumer Place values your Feedback and we operate on the basis of a continuous improvement model. Send your feedback on this brochure or our website to any contact point detailed below.

#### Contact Our Consumer Place

Email: service@ourconsumerplace.com.au

**Telephone:** (03) 9320 6839

Physical Address: Our Community, 51 Stanley Street, West Melbourne VIC 3003

Postal address: PO Box 354, North Melbourne VIC 3051