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Foreword

In 1992, when all Australian Health Ministers agreed to the National Mental Health Strategy, the reduction of stigma and discrimination and the participation of consumers and carers in decision making were recognised as key underlying principles for mental health service reform. Much has been achieved since 1992, both in increasing community understanding of mental illness and in recognising the knowledge and experience that consumers and carers have of mental health services. The Community Development Project is a major national project funded under the Strategy with the aim of enhancing community sector advocacy and embedding the role of consumers and carers in the mental health system. It was born of the commitment to facilitate consumer and carer input and influence. *The Kit, a guide to the advocacy we choose to do*, is the product of that commitment and a response to the consumer- and carer-identified need for improved advocacy skills. It is also the result of the efforts of many people, including many consumers and carers, working hard to confront barriers and to support the delivery of quality mental health services.

Much work remains to be done, however, in promoting positive attitudes about mental illness and in ensuring that consumers and carers have a genuine voice and place at the mental health service table. The second National Mental Health Plan, a second five year plan outlining ongoing mental health reform, reaffirms the Government's commitment to establishing mechanisms to facilitate consumer and carer input into decision making at all levels. It is hoped that *The Kit* will be a significant support for consumers and carers wishing to develop skills and strategies for constructive advocacy on their own behalf, on behalf of those they care for, and for people with a mental illness more generally.

The right to advocacy by consumers and carers is a key right set out in the Mental Health Statement of Rights and Responsibilities, one of the foundation documents supporting the National Mental Health Strategy. I am very pleased, therefore, to commend *The Kit*, a guide to advocacy for consumers of mental health services and family carers. It is a significant step in supporting the emerging and potential roles for consumers and carers in advocacy work across the mental health system and reflects the Commonwealth's commitment to consumer empowerment, the reduction of stigma and discrimination and to ensuring the rights of people with a mental illness.

Dr Harvey Whiteford
Commonwealth Director of Mental Health
May 1998
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The Kit: A guide to the advocacy we choose to do
A resource kit for consumers of mental health services and family carers

SPICE Consulting
Second edition – August 1999
Introduction

This Kit is the product of the ‘Community Development Project’, a major national project which was conducted over 12 months during 1997 and 1998. The project was an initiative of the National Mental Health Strategy (NMHS) and was undertaken by SPICE Consulting on behalf of the Commonwealth Department of Health and Family Services.

The NMHS comprises specific strategies in a National Mental Health Plan, designed to assist in implementation of a National Mental Health Policy. The Policy is a statement by the Governments of the Commonwealth, States and Territories of Australia. It sets clear directions for development and reform in mental health services intended to result in significant improvement in treatment, care and quality of life for all Australians living with a mental illness and family carers.

An emphasis of the NMHS is on increasing and supporting the advocacy activities of consumers and carers. The thrust of the Community Development Project (CDP) was particularly in keeping with this emphasis on advocacy, including both self advocacy and systems advocacy, where these activities assist consumers and carers to participate in decisions affecting their lives, services and their own treatment.

The goal of the CDP was to enhance advocacy activity through increasing knowledge and strengthening skills within the mental health community sector. The strategy for achieving this goal was to identify required knowledge and skills, provide opportunity to acquire skills, and create advocacy resources to support consumers and carers to undertake activities which promote sustainable change – particularly in promoting positive attitudes and addressing negative perceptions about people with mental illness.

The CDP set out to create outcomes which extended beyond the life of the project itself (that is, beyond June 1998) by:

- Creating this Resource Kit as a broad basis for current and future action rather than as a narrow formula for addressing the most common ‘problems’. Thus, the Kit contains information about systems, attitudes, experiences, skills and strategies which can be used in many ways by different people who have varied and changing goals and needs.

- Developing an Infrastructure to assist with sustaining the use and continued development of the resources by gaining support and commitment from consumer and carer groups in each State and Territory to promote the use of the resource Kit.

- Commencing a Leadership Strategy which provides some consumers and carers in each State and Territory with the skills and experience to become ‘ambassadors’ for the resources – leading and mentoring their use. These consumers and carers participated in a nationally accredited Workplace Trainer Category 1 course.

- Developing and initiating a planned Dissemination/Information Strategy in each State and Territory to encourage initial awareness of the resources to kick-start consumer and carer use of the resources; and to extend the use of the resources in ways that are appropriate for State-specific and local situations.
The resources in this Kit are only one part of a broader strategy which aims to increase and support the advocacy activities of consumers and carers in the mental health sector. In turn, that advocacy strategy is one part of the larger National Mental Health Strategy.

**Values and Assumptions**

The major values and assumptions underpinning the form and content of this Kit need to be stated, in order to clarify contexts and meanings that may otherwise be open to misinterpretation. The Kit has been developed through contributions from a diverse range of people. Each contribution has carried particular beliefs and values about the nature and purpose of advocacy; and particular assumptions about, and applications of, the material. While such diversity can be stimulating, an understanding of assumptions held by the contributors provides basic reference points for people using the Kit.

- **The pursuit of rights, justice and equality of opportunity** is critically important for consumers and carers; both as individuals and within broad groupings.

- **The current balance of power in the mental health sector** between consumers and carers and those with whom they deal (including service providers, administrators and community members) is inequitable, unacceptable and culturally and structurally sustained. Advocacy activity must be directed towards correcting this imbalance.

- **The lived experiences and knowledges of consumers and carers** should be recognised, valued and respected. These experiences and knowledge can contribute, and have contributed, to improvement in the mental health sector.

- **Self advocacy** is the most appropriate and empowering form of advocacy. Generally, people prefer to express their own position rather than have other people represent them, while recognising a role for nominated representatives and supportive advocacy in certain circumstances.

- **Self-empowerment** attained through an ongoing process of acquiring and using knowledge and skills is more sustainable and enduring than the temporary feelings of success gained by responding to opportunities for participation as they arise. However, even such occasional participation can be a source of empowerment.

- **Collective advocacy activity** (engaged in by consumers, by carers and by consumers and carers working together) has greater potential for achieving significant outcomes than uncoordinated individual actions. Sometimes, though, the activities of individuals can inspire others to participate, as well as preparing the way for important changes.
‘Advocacy’

‘Advocacy’ is used in this Kit in a broad sense to refer to a wide range of activities engaged in by consumers and carers in promoting and supporting their basic human rights and their right to services and information. The following terms and meanings are used throughout this Kit.

Advocate (as in ‘John is my advocate’) – a person who actively supports another person’s cause.

Advocate (as in ‘I advocate that consumers and carers should be involved in evaluating the program’) – to provide active support to another person’s cause.

Self Advocacy – the activity an individual undertakes to represent his/her own needs/rights.

Peer Advocacy – the activity undertaken by more than one person to represent the needs/rights of his/her peers (for example, carers addressing the needs/rights of other carers).

Systems Advocacy – those activities directed specifically towards the systems, structures and forms that are instrumental in the conditions which create injustices and inequities.

Resource Development

The resources in this Kit were developed with the clear view that they would be a foundation resource. They are a tool; they are not a ready-made or a ‘one-size-fits-all’ solution to the myriad of problems, the pervading discrimination and the poor service which many consumers and carers experience.

The resources were developed using a number of principles:

● The CDP used a model of participatory action research to involve stakeholders in ongoing assessment, action and evaluation of project activities. A Critical Reference Group of three consumers and three carers (see Acknowledgments) reviewed the project’s approach and ensured maintenance of the consumer and carer focus and direction of the project.

● The CDP built on current information and knowledge. A range of national and international literature was collected which identified the continuing growth in consumer and carer advocacy and some interesting resources applicable to the CDP.

● The CDP recognised the fundamental value of consumer and carer input at all stages. Some consumers and carers were employed by SPICE; some were supported to participate in various project activities; some were members of the Critical Reference Group; others were part of the external Project Advisory Group (see Acknowledgments) which monitored the development and progress of the CDP, offered advice from various areas of expertise and facilitated access to wider networks. (Over 50 consumers and carers were directly involved in developing material, critiquing drafts and providing strategic advice).

● The CDP resources have relevance in many different ways – national and local relevance; individual and group advocacy; personal and interpersonal situations.
Humanism, hope and passion are fundamental to consumer and carer advocacy: the resources demonstrate these qualities through examining history, relating individual stories and developing resource tools to build on passion, build up hope and celebrate success. While at times this Kit emphasises strategic, pragmatic approaches to advocacy, it does so as a means to an end rather than because such approaches are highly valued.

Consumers and carers, as individuals or in groups, will interpret and shape the resources to meet their own requirements. People have differing advocacy needs, preferred styles for engaging in advocacy activity, differing ways of learning and of accessing information.

People will use the resources to develop and strengthen their own advocacy style.

Notes

1. The materials in this Kit have been developed in good faith through extensive research based on the actual experiences of consumers and carers involved in advocacy, networking and participating. They have been validated through a number of mechanisms and cross-referencing of sources. However their effectiveness in any given situation cannot be assumed.

2. The words ‘group’ and ‘organisation’ refer to similar situations; consumers and carers often use them interchangeably.

3. People’s stories are often presented as examples. They are taken from real-life situations but fictitious names have been used.

4. Some quotes are referenced to a published source. Other unpublished quotes arose through the project process and are attributed to a project participant who is listed in Acknowledgments.

5. The Kit emphasises empowerment as a universal concept and provides for substantial individual modification and interpretation of the materials; however it cannot (in its present form) meet the needs of all Australian consumers and carers. The Kit would require culturally sensitive translation and interpretation in order to be of most value to many people from non-English speaking, Aboriginal or Torres Strait Islander backgrounds.
Acknowledgments

The Community Development Project (CDP) was born out of the National Mental Health Strategy, (NMHS). Many people participated in shaping the NMHS and in making things happen ‘on-the-ground’, through both pursuing its intent and driving it beyond its original expectations. Many of these people have been consumers of mental health services and associated carers.

The NMHS created the National Community Advisory Group on Mental Health (NCAG). This group was influential in raising awareness of the need for these resources. The Australian Psychiatric Disabilities Coalition (APDC) and the Australian National Association for Mental Health (ANAMH) were also instrumental in shaping the requirement for these resources. Many individuals contributed to the push for the development of consumer and carer advocacy resources; Janet Meagher stands out as a valued, persistent and determined participant.

The Commonwealth Department of Health and Family Services responded positively to the request for resource development. Federal funding, sound project management and a continuing commitment to positive outcomes have been the hallmarks of the Department’s contribution. Linda Pettigrove, in particular, maintained a sensitive oversight of the resource development.

SPICE Consulting established a core team of consultants to design, develop and manage the CDP. The SPICE core team comprised Deborah Fullwood, Peter Gibbs, Merinda Epstein and Greg Turner. The creation of the resources was a joint effort between the team and many other people, mainly consumers and carers. Anne Olsen’s contribution was significant, and over 50 consumers and carers (and other people with special knowledge) contributed through workshops, work groups and as individuals in advising, writing and validating the developing resources.

The CDP was supported by a Project Advisory Group of consumers, carers, academics and other community sector people drawn from a number of different States.

A small group of three consumers and three carers made up a Critical Reference Group which met regularly with two of the consultants. As a group considered typical of the final users of the resources, they were charged with the task of being critical of the project process. They served to keep the consultants honest and true to consumer and carer requirements.

Melinda and Richard May of Pro Bono Publico Communications are thanked for their sensitivity and creativity in the final design and layout of the resources; and Simon Kneebone is thanked for the energy and pertinence of the cartoons.
The following people have agreed to be acknowledged:

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How to use this Kit

What is in the Kit?

The Kit has the following parts:

An Introduction which provides a background and context to the materials and to the history of the Community Development Project.

How to use this Kit (this section) which describes the various sections in the Kit and makes suggestions to gain best use from the materials.

A separate booklet which discusses Knowledge and Attitudes that have an impact on the experiences of carers and consumers today. There are nine Knowledge and Attitude areas; within each, different viewpoints may be presented and discussed. Some areas provide background to the history of consumer and carer movements in Australia, the United Kingdom and the USA; some provide information about the challenges of undertaking advocacy, based on consumers’ and carers’ experiences; some take account of external influences such as the higher education system and the broader community.

A series of Skills and Strategies which can be selected, mixed, matched and adapted. The skills, strategies and related tools are numbered and grouped into five clusters to assist with their practical application:

- Advocacy and the individual
- Getting organised
- Some specific activities
- Advocacy and the organisation
- Getting strategic

Each skill and strategy item has both practical and motivational information including a brief background, some concrete ideas and often a tool like sample forms, tables and diagrams, actions to try, reminders and questions for you to consider.

A Glossary of key words which are particularly useful or which have been used in a specific way in the Kit. Some of the words are jargon, discriminatory or used in one State of Australia but not another. Their inclusion in the glossary does not imply that they are ‘preferred’ or that they should be used; it simply provides an explanation for the word.

A Bibliography of materials specifically referred to in the Kit, and others which are useful as broader background.

An Index which allows you to locate all references to a topic. The page numbers in the index refer to the numbered pages in Skills, Strategies and Tools unless they are preceded by the word ‘booklet’, in which case they refer to the pages in the Knowledge and Attitudes Booklet.
Why is the Kit so big? How do I get started?

The Kit is a response to the needs that carers and consumers identified. It holds a lot of information. It has been developed to appeal to the different learning styles of readers and the different goals people may have in using the materials. Thus, some material is repeated in the Kit in different ways. Some material is also repeated because it is important to read it right there on that page in relation to that issue, rather than turn to a cross-reference.

Although the Kit is big, some readers may choose to work their way through the Kit; most people, however, will use different sections in response to issues and situations as they arise. Some views or issues are linked to other material in the Kit via the skill or strategy number [for example, ‘Also see 3.1: Presentation/education’] or via the knowledge and attitudes area [for example, ‘Also see: Consumer and carer movements in the Knowledge and Attitudes Booklet’].

Here are some examples of the needs expressed by consumers and carers and how they might use the Kit.

Lydia often feels upset that the mental health professionals that she has contact with during periods of illness do not have much understanding of the things which she feels are most important to her recovery. She knows that some consumers and carers have been invited to talk to students completing their professional education at university. She feels that if she and others can be involved more fully in developing, delivering and evaluating the education provided to students, new generations of mental health professionals will be better equipped to assist consumers in their recovery process.

Lydia has heard of the Community Development Project resource Kit. She decides to look through it to see if it can provide her with some knowledge about how universities operate. She also wants to develop some skills and strategies so she can confidently approach various university departments with her ideas.

Lydia first reads ‘The higher education system’, in the Knowledge And Attitudes Booklet which provides her with an awareness of how courses are structured for the five core mental health disciplines, the opportunities for consumer and carer participation and the barriers to participation. Lydia feels encouraged; she realises that there is a place for consumer and carer participation in the higher education sector, and she begins to generate some ideas on how this can be achieved. She scans the list of contents to see which Skills, Strategies and Tools sections are most applicable to her needs.

She develops a list of skills she wants to develop: ‘How to influence people’, ‘Interpersonal communication’, ‘Presentation/education’ and ‘Finding relevant information’.

Lydia realises that many of the skills and strategies in the CDP Kit are useful to her over time and in different ways.
John has a daughter who has recently been diagnosed with a mental illness. He is finding that he needs to be with her and his wife at various times of the day in what is a stressful situation for all the family. John is having difficulty getting so much time off work, which is increasing the stress he is experiencing as the sole income earner for the family. He tries to negotiate flexible working arrangements with his employer; however he gets the feeling that they have some very negative attitudes towards mental illness, which is reinforced when he overhears colleagues joking about his daughter.

John contacts several community mental health organisations and discusses the situation he is in and inquires if assistance in negotiating with his employer is available. Unfortunately, no organisations are able to assist in this specific area although they have much to offer John in other areas of need. However, several organisations discuss with John the Community Development Project resource Kit and suggest that he looks through it and takes photocopies of sections which he feels may be useful.

After looking through the Kit, John decides that he will have a go at starting up a group for people in his situation in order to work with individual employers and employer groups to achieve an equitable outcome for all. John decides to photocopy several knowledge sections of the Knowledge and Attitudes Booklet, including ‘Consumer and carer movements’, ‘Some forms of consumer and carer participation’, ‘Engaging networks and organisations’ and ‘The broader community’. After looking through the list of contents of the Skills, Strategies and Tools sections, he decides to make copies of ‘Starting up a group’, ‘Developing your group’, ‘Creating networks’ and ‘Gaining support and fundraising’.

A group is formed and as new members become aware of the resource Kit, more sections are utilised for both the work of the group and the needs of individuals within the group.

At the meeting of the Springfield Consumer Action Group, members express concern at some recent media reports which they believe reinforce the negative, stereotyped image of people with mental illness. The group decides to embark on a campaign to work with the media to promote positive reporting of stories on mental illness and people with mental illness. The group has access to the Community Development Project resource Kit and contacts the ‘ambassador’ who has completed the accredited training course on using the resources. She is very willing to assist the group in getting the most out of the Kit.

Meanwhile, the group identifies several areas of knowledge which members consider will be most useful from the Knowledge and Attitudes Booklet including ‘Undertaking advocacy’, ‘Some forms of consumer and carer participation’, ‘The challenges of advocacy’ and ‘The broader community’. The group then identifies several Skills, Strategies and Tools sections including ‘Working with the media’, ‘Developing a campaign’, ‘Promotion’, ‘Getting yourself and your organisation focused’ and ‘Strategic thinking in targeting the message’.
In conclusion

You may not agree with all the statements or views expressed in the Kit materials. You may find them too simple or too vague or more suitable for someone else; or you may think, ‘Yes, but…..’. You may feel that the materials do not do justice to a particular situation. You may find some of the writing styles easier to read than others. Remember, the materials are a foundation, and if they prompt you to think and to question and to try something, then that is a start. You may want to try some things on your own; use some strategies and tools with a friend; use the resources as a basis for ongoing discussion and exploration within a group; enlarge a single quote or use a cartoon to prompt discussion; or take parts of the Kit and construct new ways of thinking and doing. You may make modifications and additions to the Kit that can be circulated and used by others. There is no one way for this Kit to be used. How are you going to get started?
This booklet is part of a Kit, which is the product of ‘the Community Development Project’, a major national project which was conducted over 12 months during 1997 and 1998. The project was an initiative of the National Mental Health Strategy (NMHS) and was undertaken by SPICE Consulting on behalf of the Commonwealth Department of Health and Family Services.

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The goal of the CDP was to enhance advocacy activity through increasing knowledge and strengthening skills within the mental health community sector. The strategy for achieving this goal was to identify required knowledge and skills, provide opportunity to acquire skills, and create advocacy resources to support consumers and carers to undertake activities which promote sustainable change – particularly in promoting positive attitudes and addressing negative perceptions about people with mental illness.

The other parts of the Kit are clipped in the folder.

- An Introduction
- How to Use the Kit
- Skills, Strategies and Tools which can be selected, mixed, matched and adapted
- A Glossary
- A Bibliography
- An Index
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Knowledge and Attitudes Booklet

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Consumer and carer movements

A brief exploration follows of some recent history in consumer and carer participation; the formation of self-help and advocacy groups and the ways that these have contributed to changes in mental health systems and services and in community attitudes.

‘When people not used to speaking out are heard by people not used to listening, then real changes can be made.’ John O’Brien

This section has been written to give people an idea of the changes that have been made in mental health services and community attitudes through consumer/carer participation and involvement. This section is not presented as being representative or in any way definitive. These examples are limited to three English-speaking countries: Great Britain, USA and Australia. Even then it is not claimed that all the groups and organisations in those countries are covered. What this section tries to do is produce a range of information from various sources (such as published material and the Internet), as well as draw on some first-hand accounts of how things have changed in Australia. Those who have contributed their personal reflections are only a few of the many individuals who have struggled against huge odds to improve mental health services and their delivery.

Great Britain

A note on terminology: in Britain the most commonly used terms for people who use or have used mental health services are ‘user’ and ‘survivor’.

The Petition of the Poor Distracted People in the House of Bedlam lodged in 1620 is probably the earliest recorded British example of protest against the abusive treatment meted out to mentally distressed people.

In 1845, a group of ex-patients formed the Alleged Lunatics’ Friend Society in an attempt to combat the oppression of British psychiatric patients and ex-patients. There are other early examples of individual advocacy (including self advocacy) but there is insufficient space here to include them.
Many different liberation groups and movements grew out of the politically and socially radical 1960s and 1970s. Mental health service users were rather slower to get organised than some other groups; perhaps due to the extent of their socio-political devaluation (almost to the point of invisibility). But from the 1970s on, small groups of mental health workers, patients and carers began to come together in an effort to change things.

During the late 1960s and into the 1970s, a number of groups critical of psychiatry, and influenced by Thomas Szasz, David Cooper and RD Laing, were formed. The British Network for Alternatives to Psychiatry and People Not Psychiatry were two such groups whose membership included mental health workers and patients. Around the same time the first patient-only or patient-led groups were also formed, including the Mental Patients Union and PROMPT (Protection of the Rights of Mental Patients).

The turning point for the British psychiatric survivors’ movement was a conference run by the World Federation of Mental Health and MIND (the national mental health charity organisation) in 1985. This conference was the first time that radical anti-psychiatry groups had been invited to a major mental health event. Ex-patient and radical mental health worker groups from the USA, Italy and Holland also attended this conference. From this point, many local consumer groups were formed, as well as several national networks for users of psychiatric services.

**British national networks**

**Survivors Speak Out**

The first national network of consumers and their allies was Survivors Speak Out (SSO). SSO was founded in 1986 by a group of mental health service users and workers. The term ‘survivors’ was chosen to represent a positive image of people in distress: SSO’s purpose is to **promote self advocacy** and its aims and objectives are:

- To raise consciousness of the survivors’ movement and its philosophies among users and ex-users of psychiatric services,
- To raise public awareness of alternative ways of looking at mental health and emotional distress,
- To improve understanding of distress and different views of reality among mental health professionals,
- To promote the ever-increasing number of survivor-led services within the community,
- To press statutory services and voluntary agencies to recognise the need for meaningful involvement of current and former users in the planning, provision, monitoring and evaluation of services,
- To promote self advocacy as the goal of all other forms of advocacy,
To support the formation of new survivors’ action groups,
● To promote positive images of survivors through the media,
● To provide and contribute to workshops, training events and conferences on these issues.

SSO believes in informed choice for all treatments and a right to refuse. People have a right to know the effects of drugs and the alternatives to them.

SSO publications include the *Self-Advocacy Pack* first produced in 1989.

**MIND**

MIND (established in 1946) is the leading non-government mental health association in England and Wales. MIND campaigns for the right of people living with mental distress/illness to lead an active and valued life in the community and is an influential voice on mental health issues. There are over 220 local MIND associations around the country.

MIND is the largest voluntary sector provider of community care and draws on the experience and skills of mental health service users, carers and professionals.

Local MIND associations offer many services including supported housing, crisis help lines, drop-in centres, counselling, ‘befriending’, advocacy, and employment and training schemes.

MIND advises government, public health and local authorities on good practice, services and developments in mental health and community care. MIND’s policies are always developed in consultation with the *MINDlink User Network* and allied organisations.

MIND also provides a special legal service to the public, government, lawyers and mental health workers. The nationwide *Legal Advice Network* involves over 600 lawyers who work on cases relating to mental health issues.

Some important MIND publications are: *MIND User Involvement Information Pack; MIND Policy on User Involvement; MIND Guide to Advocacy; Guidelines for Empowering Users of Mental Health Services*

**MINDlink – the user network of MIND**

MINDlink is a user-only pressure group within MIND set up in 1988 with four main purposes:

● To have an input into MIND policy and campaigns through regular consultation and representation,
● To act as an information and contact network for MINDlink members,
● To put forward suggestions for MIND’s future work,
● To elect the members of the national MINDlink panel.

MINDlink representatives are elected onto MIND’s Regional Councils, the Policy Committee, Council of Management and the Conference Committee. Where members are willing, there are opportunities to speak with the press, TV or radio.

Some members also run workshops and/or speak at conferences. The MINDlink regional representatives and the coordinator provide support to help people move into these areas. Training is provided locally and a new program of training is planned for the future.
UKAN (United Kingdom Advocacy Network)

UKAN came into being as a result of a 1990 conference organised by the Nottingham Patients’ Council Support Group and the Nottingham Advocacy Group. The aim of the conference was to explore the possibility of establishing an independent national body to represent and support patients’ councils, advocacy projects and user forums involved in planning and monitoring mental health services. The idea of a National Advocacy Network was inspired by the work of patients’ council support groups, which, in turn, were inspired by the Dutch model. In Holland every hospital must, by law, have a patients’ council. The body which coordinates these councils and the main consumer organisation, Clientenbond, are both government-funded.

A nationwide steering group was mandated at the 1990 conference to organise the first National Advocacy Network conference, and this took place on January 24-25, 1991 in Nottingham. The conference (attended by 80 percent users and 20 percent ‘professionals’) voted to establish a National Advocacy Network as a confederation of independent groups with its initial administrative base in Nottingham.

Full membership of UKAN is open to mental health service user/survivor-led groups and affiliation is open to groups with expressed goals of mental health service user empowerment that deliver advocacy for service users. At the UKAN annual general meeting, voting rights are available only to groups controlled by mental health service users/survivors.

UKAN attempts to work closely with other user/survivor groups, notably Survivors Speak Out and MINDlink. Representatives from other organisations regularly attend UKAN management committee meetings and UKAN representatives are involved with a number of other organisations in both the voluntary and statutory sectors of mental health provision.

UKAN’s aims and objectives are:

- To be a national confederation of autonomous patients’ councils, advocacy projects and user forums which actively promote user empowerment and involvement in the choosing, planning, monitoring and running of mental health services,
- To collect and disseminate information about patients’ councils, advocacy projects and user forums for people who are present and past recipients of statutory voluntary or private mental health services in England, Wales, Scotland and Northern Ireland,
- To collect information about possible funding agencies and to give such information and assistance to groups trying to obtain funding for advocacy projects, patients’ councils and user forums,
- To support with information, advice and network contacts, any individual or group planning to form a patients’ council, advocacy project or user forum,
- To lobby the government, international regulating bodies, health authorities, social services, local authorities, housing agencies, voluntary services and other agencies to provide facilities, funding and support for patients’ councils, advocacy projects and user forums wherever services to people in emotional distress exist,
To inform and educate the public and professionals about the work of the UK Advocacy Network (UKAN) and member groups; to publicise this work in order to change public and private attitudes towards mental health service recipients and their organisations and to demonstrate the necessity for and the effectiveness of patients’ councils, advocacy projects and user forums,

To hold conferences, seminars, training sessions and courses and other meetings to bring people together who are involved, or plan to be involved, in working in user-led projects for the purposes of mutual support and information-sharing; or to inform and educate mental health workers and other professionals about their work,

To obtain funding for workers and national and regional resources centres to develop advocacy-related services and groups nationwide,

To work for and promote user participation and independent advocacy wherever there are people designated as having mental health problems, including mental health units and community based schemes for assessment and care management, whether statutory, voluntary or private (for example, private hospitals, clinics and residential homes),

To have a clear and explicit policy of equal opportunities,

To hold regular national conferences at which the policy of the UKAN will be determined by representatives of user groups,

To work cooperatively with other national user-led groups that share a similar commitment to the promotion of advocacy and user-empowerment,

To work for and be part of an international network,

To lobby for a national Bill of Rights and for the implementation of legislation to ensure every recipient of mental health services has free access to independent advocacy.

Some other important British groups and networks

- The National Black Mental Health Association
- Good Practices in Mental Health
- Manic Depression Fellowship
- Hearing Voices Network
- The Scottish Users Network (SUN)
- Voices Forum (National Schizophrenia Fellowship’s user network for people with a schizophrenia diagnosis)
- National Schizophrenia Fellowship
- Mental Health Media Council
- King’s Fund Centre (funding and information for health/mental health projects)
The United States of America

A note on terminology: in the USA the terms ‘ex-patient’ and ‘survivor’ usually refer to people who have had particularly bad experiences within the system and no longer use conventional services and treatments. The term ‘consumer’ refers to those who do actually participate in the system. In Australia we tend to include both categories within our use of the term ‘consumer’.

Mental health advocacy in the USA really began in the late 1960s when ex-mental patients (then calling themselves ‘ex-inmates’) formed small groups in Northern California, New York, Massachusetts and Kansas. This early ‘advocacy’ was simply groups of former mental patients meeting together in church basements or in each others’ homes doing ‘consciousness-raising’ and mutual support.

Somewhat later these early activists – such as Judi Chamberlin, Howie the Harp, Sally Zinman, Su and Dennis Budd and many others – staged acts of civil disobedience, such as chaining themselves to the gates of mental hospitals and ‘liberating’ people from mental hospitals simply by entering and taking the person out.

These people were the pioneers of the movement which is now called mental health advocacy. Their actions brought about the first national publication by and for mental patients, *Madness Network News*, which was published in San Francisco for approximately 10 years. With virtually no money, no grants and no outside support, groups began springing up all over the country. Some groups became oriented towards self-help and mutual support; others focused on opposition to psychiatry; most groups included both these elements.

A conference called the *International Conference on Human Rights and Against Psychiatric Oppression* was held annually, often at camping grounds or on college campuses. These were organised and run by activists in the growing movement.

In the late 1970s, the US Federal Government began to take notice and the States were encouraged to support these groups through small grants. The Community Support Program was developed within the National Institute of Mental Health (now the Center for Mental Health Services). It was charged with involving more people who had experienced psychiatric services in policy making and program development. The term ‘consumer’ came out of this, and in 1984, the first national Alternatives conference was held. This was a meeting of people who had first-hand experience of the mental health system; they ran workshops for each other on how to start self-help groups, how to raise funds and other topics relevant to self-help.
However, this conference also marked the beginning of the split between ‘consumers’ (primarily clients of Community Support Programs) and ‘ex-patients’ (who now call themselves ‘psychiatric survivors’) who rejected the system. There are now numerous ‘consumer’ groups, which are often dependent on State or Federal money for their survival. At the same time, many outspoken ‘survivors’ still remain active and involved in the larger movement.

In the meantime, advocacy programs were being formed in some States, with State or County funding. One of the earliest internal (that is, within a hospital) advocacy programs was founded in Minnesota by Bill Johnson (a social worker), who convinced the administration to allow him to open an ‘advocacy office’. In Pennsylvania, lawyer David Ferleger sued the state on behalf of all the residents of one state hospital – and won. Ohio had also established a ‘patients’ rights’ service.

Around the same time, the Mental Health Law Project (now called the Bazelon Center) in Washington, DC was attempting to have an impact on mental health services by taking on individual cases and class action suits. In 1980, a group of these advocates, many of them lawyers, met and formed the National Association for Rights Protection and Advocacy (NARPA).

NARPA is the only independent advocacy organisation in the USA. Its regulations state that at least one third of the members of its board of directors must identify themselves as current or former recipients of mental health care. The membership includes lawyers, non-legal advocates and ex-patients, including many people whose roles overlap. NARPA publishes a quarterly newsletter, The Rights Tenet, and holds an annual conference offering cutting-edge information to its members and allies.

In 1985, the US Congress held hearings about conditions in State mental hospitals and other treatment programs. A bill was passed to create a formal advocacy program in each State and Territory to serve people with psychiatric disabilities. Most of the programs (called PAIMI – Protection and Advocacy for Individuals with Mental Illness) became part of already existing advocacy programs for people with developmental disabilities. Some became part of State agencies and a few became independent, freestanding agencies. Funding was minimal and services were limited to those who were currently hospitalised or who had been hospitalised within the past 90 days. Perhaps the most important effect of this legislation was its requirement that at least 50 percent of the membership of the advisory councils to each PAIMI program be current or former recipients of mental health services or their family members. Some States initially tried to circumvent dealing with ‘mental patients’ and only recruited family members. This led to the development of regulations requiring participation from consumers, psychiatric survivors and ex-patients.
The National Empowerment Center

The National Empowerment Center (NEC) is particularly concerned with informing people who have been diagnosed with mental illness about recovery, empowerment, hope and healing. The NEC attempts to provide people who are mental health consumers and survivors with information and resources they might need to regain control over their lives.

The NEC provides a number of resources including an information and referral service that people can call to receive information about consumer/survivor resources in their area. This service also offers information about selected topics, such as holistic alternatives to symptom management, and how to form self-help mutual support groups.

In addition the NEC offers:
- A national directory of mutual support groups, drop-in centres and state-wide organisations,
- Networking and coalition-building,
- Staff available for workshops, public speaking and technical assistance,
- Education and training to providers from a consumers/survivor perspective,
- A database with hundreds of topics of interest to consumer/survivors,
- A toll-free line to access information.

National Mental Health Consumers’ Self-help Clearinghouse

The Clearinghouse pursues the following activities:

Information and referral

The Clearinghouse handles numerous enquiries concerning the needs of the consumer/survivor movement. Consumers, family members, professionals and other interested people request information about everything from locating local groups to how to get more involved in the self-help movement. The Clearinghouse has contacts who provide technical assistance in forty states, in Puerto Rico and in Canada.

On-site consultation

The Clearinghouse provides on-site consultation for self-help project development.

Training events

The Clearinghouse has organised several national conferences and national and regional teleconferences, and has co-sponsored several additional national conferences. The Clearinghouse provides training that focuses on issues affecting consumers/survivors. Training topics include fundraising, leadership development, public relations, self-help group development and many others.
Publications

In addition to the Consumer Library, the Clearinghouse has developed and printed many technical assistance pamphlets and manuals on mental illness and the self-help consumer movement, including such titles as: *Consumer-Run Drop-In Centers; How to Develop a Consumer-Run Newsletter; How to Start a Self-help/Advocacy Group* and many more.

The Clearinghouse has an **electronic mailing list** called **The Key** for the purpose of sharing developments in the consumers’ self-help movement and encouraging discussion around consumer issues.

Justice In Mental Health Organization

The Justice In Mental Health Organization Inc (JIMHO) is a non-profit organisation founded in 1980 by individuals who are, or have been, consumers of the public and/or private mental health systems. It is an advocacy group, as well as a mutual self-help organisation, that offers a network of support to individuals living in the community. JIMHO has twenty-five affiliated consumer-run drop-in centres.

JIMHO advocates for the rights and dignity of all people living with mental or emotional illness. The organisation is concerned with justice in family, housing, employment and social life, as well as with civil and legal rights.

JIMHO also works as a consultant with State agencies, researchers, mental health professionals and consumer organisations in helping to develop, empower and promote consumer-run alternatives.

Family carers in the USA

**NAMI (the National Alliance for the Mentally Ill)**

NAMI began when 254 people, whose families included a member who had been diagnosed as suffering from a mental illness, met in September 1979 to consider how to help themselves and their relatives. Although there were a number of concerned and caring professionals and providers in attendance, the founders wanted to make NAMI an organisation governed for and by families and consumers.

NAMI is an incorporated non-profit organisation run by a board of directors. Early efforts centred on making connections with small family support groups across the country. An annual conference was planned and a newsletter was published. Early leaders of NAMI demanded accountability from a government that was not making a significant investment in either services or research focused on mental illnesses.

NAMI families found courage and hope in joining together to advocate for needed changes in public policy and attitudes.
A note on terminology: in Australia the term ‘consumer’ includes all those who have received services and/or are still receiving services, or, when in need, have been refused services. The term includes those who seek alternatives to the prevailing system and treatments. Some people choose to call themselves ‘survivors’.

The role of national bodies

Although there have been somewhat variable patterns of consumer and/or carer organisational development in the different Australian States and Territories, national bodies concerned with mental health issues have accomplished much. These organisations have been pivotal in setting the national agenda, and in helping to create an environment in which Federal policy makers eventually had to respond to growing concerns within the mental health sector.

Australian national bodies emphasised social justice, human rights, standards of service, the need for a consistent nationwide mental health policy, the need for prevention strategies and the need for public awareness programs.

Australian non-government organisations also conducted or commissioned their own research projects to illustrate the needs and anomalies of a system which was, at that time, inadequate and unstructured. Over the last two decades they have set the scene for what is now known as the National Mental Health Strategy.

Among those influential national bodies, a few, including ANAMH (Australian National Association for Mental Health), Schizophrenia Foundation and GROW, had strong consumer/carer representation and input on their boards of management. This was despite the fact that, at that time, consumers and carers were not separately organised in groups, nor were they necessarily recognised as a ‘power base’.

Early consumer and carer participation

One of the earliest ‘mental health’ action groups in Australia was CAPIC (Citizens Against Psychiatric Injustices and Coercion), which was formed in Victoria in the early 1970s. This radical group staged demonstrations and various other forms of protest, including ‘liberating’ people from institutions and confiscating ECT (electro-convulsive therapy) equipment.
The first family support group in Australia was NSW ARAFMI (the Association of Relatives And Friends of the Mentally Ill), founded around 1975. In Queensland a discussion group for families who had a member with a mental illness became Queensland ARAFMI in 1977. The driving motivation for the foundation of these groups was the dismal lack of recognition, support and information for family carers from services then in place.

’Parents were blamed for their offspring’s mental illness and, therefore, professionals did not communicate with families. Very little information was given to family members regarding medication, symptoms, etc, so families floundered and made awful mistakes.’ Roma Drummond

The Schizophrenia Fellowship of Victoria was founded by Margaret Leggatt and incorporated in February 1978. It grew from meetings between three or four families, each with a family member who lived with a mental illness. This modest beginning was a forerunner of the family support groups which continue to contribute a very valuable service, providing education and ongoing support.

Through these groups, family carers were able to share their experiences with others who were living in a similar situation, who really understood and were willing to listen. When families gained information about disorders and some guidelines for coping, the first steps towards family carer advocacy began.

Victorian ARAFEMI (the E stands for ‘Emotionally’) was incorporated in October 1979. Two of the prime movers in establishing ARAFEMI were Joan Robertson (social worker and coordinator of Mental Health Support Services in Victoria) and Georgia Shields. Joan Robertson, who was dedicated to the ideal of self advocacy by mental health consumers, also played a significant role in helping to set up VMIAC (Victorian Mental Illness Awareness Council). The Victorian Schizophrenia Fellowship, ARAFEMI and GROW also gave support to this project.

VMIAC is the peak consumer advocacy organisation in Victoria: members include consumer groups as well as some individual consumers. VMIAC was officially formed in July 1982. It originated in the work of a group of consumers and their allies who wanted to give a higher profile to the needs of people living with psychiatric ‘disabilities’. In the early days VMIAC included a radical arm called the PCU (Psychiatric Clients’ Union).

VMIAC’s role was to help set up self-help groups around the State and to act as a coordinating body. Between 1989 and 1994, VMIAC also organised forums and invited non-voting consumers, as well as providers and administrators, to committee meetings.

VMIAC has been involved with systemic, group and individual advocacy. It has also been active in consumer-perspective research, service evaluation and education and has produced a Declaration of Rights of People with Psychiatric Illness.

Some important VMIAC publications are: Unlocking the System (1990); Listen to Our Voices (1992); Reports of the Understanding and Involvement (U & I) Project, 3 volumes (1994-1996); Developing Effective Consumer Participation in Mental Health Services: The Report of the Lemon Tree Learning Project (1997).
Some highs and lows of participation in the early days

Despite the existence of the early groups, very few consumers or carers were involved in organised activism and mutual support of any kind. There was very little support from professionals for people who had a mental illness and wanted to lobby for improved services. Consumers and carers were given little access to factual information about services; there was no sense of accountability of services to consumers and their families. At this time very few people with mental illness gave talks to service providers. If they did so, the talks were usually of a ‘testimonial’ type. A few early consumer activists, such as Simon Champ from NSW, were able to turn these limited opportunities into something more: to make people think about issues and context.

The early efforts of ‘mental health activists’ were in opposition to existing structures. It was only in 1991 or 1992 that it became fashionable to talk of ‘partnership’ and consumers really began to embrace this philosophy. For those involved in the early 1980s there was a different kind of pressure. What these individuals were doing (such as consumers giving talks to mental health professionals) had never really been done before.

An additional pressure experienced by the early activists was the feeling that, if what they were doing was successful, it would become routine practice for providers to listen to what consumers had to say.

There were a few professionals, like Dr John Hoult and Dr Alan Rosen in NSW, who had visions of consumer involvement based on what they’d seen in Britain and the USA.

In NSW two consumer-orientated groups were active during the early 1980s: PALA and Dr Meg Smith’s Manic Depression support groups. PALA was anti-psychiatry and was strongly influenced by the ideas of Thomas Szasz and RD Laing. PALA regarded medication as a tool of social control, ECT as cruel and barbaric and involuntary hospital admissions as an infringement of rights.

In some States, for some consumers, the lack of organised mutual support and action persisted into the late 1980s. In Queensland, as late as 1987, consumer activism was largely informal. Connections were made with those who became friendly in different hospital settings and decided to remain close in the community.
One reason for the slow progress of consumer-led organisations was that, throughout the 1970s and 80s, treating professionals (especially those in private practice) commonly discouraged people with mental illnesses from associating with each other. Yet those consumers who challenged this advice benefited from the ‘peer support’. It was through sharing their experiences that some people began to see the possibility of true recovery. Additional reasons were that, as in other countries, people who lived with mental/emotional distress were a seriously disempowered and marginalised population; and many people did not dare to ‘come out’ because of social stigma.

Participation from 1985

In 1985, NSW Schizophrenia Fellowship was formed. From the beginning the organisation actively encouraged consumers to be on management committees. The Fellowship had an enormous impact for many people with schizophrenia and their relatives. Large public meetings were attended by hundreds of people. It was the beginning of a real ‘coming out’ of people with a mental illness. People found, with great relief, that there were others who were motivated to change the mental health system.

The emphasis of the Fellowship was on education, lobbying and awareness. But there were lots of barbeques, some just for people with schizophrenia. It was at some of these that a number of early consumer activists cut their teeth on discussion and argument.

The Mental Health Legal Centre (Victoria) came about through the Victorian Mental Health Act proclaimed in 1986. Lawyers at the centre are specialists in the mental health area and the staff includes consumer advisers.

Some of the key achievements of the Centre include:

- Monitoring, dissemination of information and advocacy regarding significant recent changes to the Mental Health Act,
- Informing consumers of their rights, with special bulletins and pamphlets, especially regarding medication and involuntary admissions,
- Legal representation for a number of consumers in legal matters related to their mental health,
- Community education about mental health legal issues and consumer rights, with many educational events and publications for consumers and advocates.

During the late 1980s in NSW, AFTERCARE, a non-government organisation that houses people who have a mental illness, ran a number of forums for consumers. Consumers were invited as speakers to address various themes: sexuality, work, human rights. These forums were often attended by over 100 consumers. Although the forums were not actually organised by consumers, they were a great consciousness-raising exercise, and helped aspiring ‘activists’ gain public speaking experience. They were great for networking at a time when people were just beginning to talk about ‘rights’. Joy Said was head of AFTERCARE and was very ‘consumer friendly’ and empowering in her philosophies regarding consumers.
In Queensland towards the end of the 1980s, a consumer group called **Step Out of the Shadows** was set up, run and directed by consumers. The group effected some excellent support and advocacy work with other consumers and was very much the quasi-consumer peak reference group prior to the establishment of formal advisory mechanisms. The group became respected in the community beyond consumer boundaries. The group no longer exists, but many of its former members are still active in the ‘consumer movement’ in Queensland.

The **Australian Mental Health Consumer Network (AMHCN)**, initiated in September 1996, aims to represent consumers at a national level as the **peak consumer body** in Australia. This Network remains independent of service providers and is managed by consumers for consumers. The Network is directed by a committee consisting of representatives elected from all States. At present the Network is pursuing ongoing funding to extend its work.

**OZMAD** is an e-mail information dissemination and discussion list for people interested in the Australian mental health consumer/survivor movement.

The focus of the list is Australia-specific: Australian events, issues and legislation. Discussions of State-specific issues and events are arranged within topics.

OZMAD can be seen as the electronic arm of the Australian Consumer Network, but involvement is not restricted to formal members of the Network. All Australian consumers/survivors are welcome, and other interested people may join with the agreement of the list.

**Mental Health Law Centre** (WA Inc): In March 1995, a concerned consumer contacted Legal Aid WA regarding the availability of specialised services for clients who were or had been consumers of mental health services.

This contact led to a meeting between the **Lorikeet Clubhouse** and **Legal Aid**, following which a three month trial project was implemented. During the trial, Legal Aid and Community Legal Centre solicitors operated an advice service at the Clubhouse one afternoon each fortnight. The trial was so popular it was fully booked six weeks ahead.

The evaluation of the trial gave many examples of why Legal Aid WA felt it necessary to be involved:

> ‘Consumers of mental health services are notoriously disadvantaged by legal self advocacy. The effect of illness and medication can severely disadvantage such people in putting a case forward in the most cogent and effective light. In addition, many patients are also disadvantaged by their suspicion of institutions (including the law) and are often accustomed to being unheard or misunderstood. These characteristics further inhibit both the patient’s ability to put their wishes forward and the patient’s expectations of what can be achieved.’  
>  
> Legal Aid, WA, 1995
Following the success of this trial, the Mental Health Law Centre (WA Inc) was established in November 1997.

Other consumer and carer initiatives

Not all developments within consumer and carer movements have occurred in the State capitals, or under the auspices of large organisations. Various groups from rural areas have developed important local projects and their efforts have not gone unnoticed. Although it is impossible here to name all the groups and their projects, it is important to recognise the ‘ripple’ effect. That is, to appreciate the growth in numbers of people becoming involved in developing support services and advocating for effective resourcing of mental health service delivery.

The National Mental Health Strategy, CAGs and NCAG

In 1992, an historic decision was made by Australian Health Ministers to adopt the National Mental Health Policy and Plan. This followed the earlier endorsement of a Mental Health Statement of Rights and Responsibilities. These three documents, together with Schedule F1 of the Medicare Agreements, form the National Mental Health Strategy.

The Strategy is a commitment by Australian State, Territory and Commonwealth governments to improve the lives of people with a mental illness.

The National Mental Health Strategy includes the commitment to consumer and carer participation through the establishment of a National Community Advisory Group on Mental Health (NCAG) and State and Territory Consumer Advisory Groups (CAGs). NCAG is the mechanism through which consumers and carers have provided input into the National Mental Health Strategy.

NCAG was established in September 1992 by agreement between Australian Commonwealth, State and Territory Ministers for Health. Consumer Advisory Groups (CAGs) have since been established in every State and Territory to provide advice to the various ministers for health.

The establishment of CAGs and NCAG as part of the National Mental Health Strategy has helped give the consumer and carer movements genuine political clout.

The NCAG and its State/Territory equivalents have not existed without controversy from within the consumer and carer movements. As committees whose members are appointed by Ministers of Health, they have been criticised for being top heavy: serving a vision which has come from the top down rather than from the grass roots up. There has been much misunderstanding about their role, and some consumers and carers have had trouble coming to terms with the fact that they are ministerial advisory mechanisms set up to give a consumer and carer viewpoint on important policy creating structures at the State and Federal level and were never designed to be representative.
On the positive side, the State and Territory CAGs have been successful in bringing carers and consumers to the same table. They have encouraged the two groups to work collaboratively. They are highly regarded overseas as an example of community input into active decision-making bodies. Perhaps the greatest impact has come from the fact that the Chair and Vice Chair of NCAG were made permanent voting members of the Australian Health Ministers’ Advisory Council’s Mental Health Working Group. This Group is made up of the heads of the mental health branches in each State and Territory. During the first National Mental Health Strategy, the Mental Health Working Group played the central role in the development of important policy directions; directions supported by the States and Territories responsible for mental health service provision.

At a national level and, more or less consistently, at a State level, decision-makers began to realise that there was no longer any such thing as a policy-determining committee without a CAG member.

**NCAG ceased to exist in December 1998.**

**1998 – and a new national peak body**

The first meeting of the interim Board of the Mental Health Council of Australia was held on 26 November 1997.

The interim Board includes representatives from indigenous, culturally diverse and rural settings, as well as four consumer and two carer representatives and representatives from professional groups. Two consumer representatives are from State CAGS and two from the National Mental Health Consumer Network. The two carer representatives are from State CAGS.

Other non-government organisations to be represented on the board include the Australian National Association for Mental Health (ANAMH), the Australian Psychiatric Disability Coalition, GROW, Schizophrenia Fellowships Council of Australia and the Mental Health Foundation of Australia.

‘The mental health sector has been historically disadvantaged by the absence of a national peak body which brings all parts of the sector to the table.’

John McGrath, Carer Representative and inaugural Chair
Conferences

The 1990 World Federation for Mental Health Conference was held in New Zealand. A number of Australian consumers attended this conference and made contact with other consumers/users/survivors from around the world. There is now regular contact between consumers/users/survivors from many different countries, enabling a wider range of issues and concerns to be addressed, and encouraging the sharing of experiences and models for participation.

1990 was also the year of the first TheMHS (The Mental Health Services) Conference in Adelaide. There were only a handful of consumers there: Adelaide consumer Tina Hatchet spoke. There were no ‘consumer only’ sessions. Some people who attended said that it was more a meeting of visionaries and alternative thinkers in mental health than what TheMHS has now become.

In 1993, TheMHS conference was held in Sydney with very few consumers attending. The low consumer attendance was, at least in part, due to lack of funds in the various consumer groups and organisations. In response to the low turnout by consumers at the Sydney conference, Victorian consumer activist, Rod Salvage, was invited to join the organising committee for the 1994 Melbourne conference. This move resulted in a consumer day being included for the first time as part of the 1994 TheMHS conference. At the 1994 conference, the first family carers’ day was also held.

The 1996 Brisbane TheMHS conference was significant for a number of reasons. A high level of consumer input was genuinely sought in establishing directions for the conference. Not only did the organising committee want a person with a lived consumer experience as a co-convener of the conference it wanted that person to be selected by consumers and not appointed by the committee.

Consumers involved in the organisation of the 1996 TheMHS Conference worked to establish a precedent regarding the level and genuineness of consumer involvement. If a consumer was to have a co-convener position, then it was important to all concerned that it was not just for ‘show’.

Highly successful Carers’ Conferences have been held in 1995 and 1997. Through coming together at these conferences, people felt united in one voice. These conferences are regarded by some carers as a turning point for families. Not only do family carers now have a voice, but that voice is being heard by the general community and by all who are involved in the wellbeing of people who live with a mental illness.
Hospitals and deinstitutionalisation

Much about institutional care has been rightly condemned, particularly the total control over the lives and liberties of people, as well as the conditions in which some people were forced to live. However, there were some positive aspects for some people at some hospitals: good activities, better safety and better stabilisation of illness. People were admitted to hospital before they became seriously ill. This is not necessarily the case these days: often people are allowed to deteriorate before a bed can be found for them.

A Victorian consumer recently remarked that she has never heard a consumer argue for a reduction in beds. There are times when some consumers feel that they will be safer in hospital. But one of the reasons this might be so is the shortage of suitable housing in the community.

‘Beds means more than just hospital beds, it means ‘beds in the community’ – that is, somewhere to call home.’  Sue Armstrong

Many people living with a mental illness live with their families. Unfortunately, and despite great improvements, there is still a lack of support, respite and other services for families. Some people without family are fortunate enough to live in good supported accommodation and to receive help through good psychosocial rehabilitation programs. However, far too many people with mental illness live in substandard accommodation or are homeless.

‘Regrettably, deinstitutionalisation has made mentally ill persons the victims of a cruel hoax. The very word itself is a typically long euphemism of bureaucrats which has actually meant cutting costs and thereby pleasing the pervading economic theories of their political masters.’  Justice Marcus Einfeld

Deinstitutionalisation began in earnest during the late 1980s and has continued through the 1990s. Because suitable community based support services were not already in place, non-government organisations had to lobby for support services to follow patients from hospital to the community.

During the 1990s, consumer and carer groups were able to slow down the deinstitutionalisation process, which many people felt was being carried out too rapidly and without sufficient planning. This was particularly so with regard to the needs of those who had been long-term patients. Family carers and consumers had gained inner strength from their support groups and so had more confidence and assertion in lobbying. As a result of this lobbying, many positive changes were implemented. The restructuring of mental health clinics during this time was also influenced by input from consumer and carer groups.
Community teams such as crisis, mobile support and **home-based outreach teams** (the various teams have different names from State to State, and even from region to region) have been an important innovation in bringing services into the community. There are, however, some difficulties attached to this kind of service.

There are **insufficient teams** and these have **insufficient staff** to adequately service the people who need help. Some consumers dislike the idea of ‘strangers’ entering their homes, saying that crisis team members are sometimes disrespectful of their privacy. Many consumers regard the crisis teams as ‘gatekeepers’: that is, these teams are responsible for deciding who goes to hospital and who does not. Consumer- and/or carer-led training for crisis and support team workers would perhaps help with these and other communication-based difficulties.

**Stigma and popular perceptions**

‘The side-effects of antipsychotic drugs are what most people see as the signs of mental illness. People who have been disabled by mental illness need to be encouraged to change the system so they can reduce the alienation and rejection of being fringe dwellers.’ Lloyd Marsh

Despite the fact that, through the efforts of consumer and carer organisations, there is now much more publicity about mental illnesses, stigma still exists both in the community and within mental health services. Some carers feel that the role of carer and the burden which carers carry has now been recognised; but they also continue to share in the burden of stigma. For this reason consumers and carers are becoming more and more involved in education of service providers, school children, the police and others.

Only 15 years ago, very very few people who experienced a mental illness would admit so publicly. Most people ‘hid’ in the community. Things have changed in this respect. The support provided by the consumer and carer organisations has allowed many consumers to ‘come out of the closet’ and participate actively to bring about change.

**Media perceptions**

In 1985, ‘The Mike Willisee Show’ included a story on schizophrenia with Simon Champ. This was probably the first time that a consumer had appeared on television to talk about the illness and was a positive step in educating the public about mental illness. However, in 1987 *The Bulletin* magazine published a story about schizophrenia titled ‘The Illness that Breeds Killers?’.

The same year (1987), prompted by the persisting misrepresentation of mental illness in the media, journalist Anne Deveson (whose son, Jonathon, was diagnosed with schizophrenia) organised a workshop for media people at the Hilton Hotel in Sydney. Many people with schizophrenia participated to educate the journalists who attended.

A number of television and radio programs featuring consumers talking about their experiences followed in the next few years. Public response to these was very strong with hundreds of letters being received by the TV and radio stations.
At the First Fleet re-enactment in 1988 (the bicentennial year), a ferry was hired for people with disabilities to be present. There were only a few people with psychiatric disabilities, but these consumers regarded their presence as ‘very symbolic of our hopes to be on the agenda of issues for the 90s’.

It is interesting to notice that, over the last ten years or so, representation of mental illness in the entertainment media has become somewhat more educated. In popular television shows there has been much less emphasis on the ‘psychotic axe murderer’ scenario. Instead Australian series such as *E Street*, *GP*, *Blue Heelers*, *Mercury* and others have featured episodes dealing with such topics as chronic depression, schizophrenia, dissociative disorder, suicide and police shootings of people living with a mental illness. There have also been some notable ‘big screen’ films made about the lives of people living with mental illness, such as *An Angel at My Table*, *Shine* and *Angel Baby*.

The importance of these kinds of representations in the popular media lies in the role the media plays in shaping the dominant culture. More realistic, less sensationalist stories about consumers, whether in factual or fictional shape, will help to dispel the old stereotypes of ‘mad, bad and dangerous’ and ‘mental illness = general incompetence’.

**Continuing change: keeping up the momentum**

> ‘It is important to remind ourselves where we have come from in order to continue the journey to where we are going. It gives us strength to see that change has occurred within a system that, historically, does not embrace change readily.’ Helen Glover

When looking at the historical developments of the consumer and carer movements, it is important to acknowledge the support and encouragement given by people who do not personally identify with a consumer/carer experience. Without this support, consumer and carer groups would remain ad hoc, sporadic, unresourced and unconnected. These non-consumer/carer supporters come from a diverse range of backgrounds. Some operate in the policy arena, some are professional colleagues, community sector members, academics, educators and so on. As consumers/carers work towards developing stronger consumer and carer movements, they now have allies among those who traditionally and historically would never have joined them publicly.

Each of the consumers and carers who so generously contributed to the information in this section has emphasised the need for further change in mental health services and in community attitudes. Many people have spoken and written of the need for professionals, consumers and carers to work together as equals providing good communication and cooperation.
‘It is vital that we all work together as advocates for those who are not able to speak for themselves. It is also important for both carers and consumers to have some skills training in advocacy and be assured of ongoing support.’ Ailsa Whitehead

Perhaps a final word of encouragement is in order:

‘When change is slow or setbacks demoralise us, it is not unusual to find members of groups becoming discouraged from working towards consumer-focused mental health approaches to care. Taking time to reflect where the “movement” is in light of where we have come from often serves to remind us that change is occurring in the big “picture”.’ Helen Glover

The following people contributed their individual stories to this section:

Sue Armstrong  
Anne Deveson  
Mike Fenton  
Margaret Leggatt  
Janet Meagher  
Yvonne Shipp  
Ailsa Whitehead  
Simon Champ  
Roma Drummond  
Helen Glover  
Lloyd Marsh  
Rod Salvage  
Irene Towler
National organisations in Australia

There has been a pleasing growth in national advocacy organisations in Australia. While some of these are not strictly consumer/carer organisations they have a very strong consumer and family carer focus. The growth and activities of the consumer and carer movements have led to greater consumer/carer representation and perspectives for these organisations.

These organisations are:

- ANAMH – Australian National Association for Mental Health
- APDC – Australian Psychiatric Disability Coalition
- GROW Australia
- National ARAFMI
- SANE Australia
- Schizophrenia Fellowships Council of Australia

These organisations have members who are consumers, carers and mental health professionals.

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- **USA**
  
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  **Australian MH Consumer Network:**  
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  **OZMAD:**  [http://www.madnation.org/ozmad.htm](http://www.madnation.org/ozmad.htm)  
Undertaking advocacy

What is advocacy?

Traditional meaning

Advocacy means different things to different people. Its plain English meaning is that advocacy is supporting another person’s cause. This idea of people representing others has gathered strength in the last 20 years, particularly in disability areas. It has been thought that sometimes people benefit from having others speak out on their behalf.

Consumers of mental health services and carers associated with mental health services have strong cause to participate in decisions about the services and to ensure that their views about a range of related issues are expressed and heard. Sometimes, perhaps when a consumer or carer is particularly vulnerable, it is useful to have someone to speak on behalf of the person.

Mental health advocacy

Where advocacy in mental health differs substantially from the traditional definition of advocacy is that consumers and carers are not generally disabled in a way that requires someone to represent them. Rather, they are capable of representing themselves. This growing assertion by consumers and carers that they are capable of advocating for themselves has given rise to growing activity by individuals and the development of a number of mutual support organisations to add strength to their ‘voice’. The mental health system is gradually responding by providing increasing opportunities for consumers and carers to effectively participate.

Advocacy in mental health is not so much about people representing other people, but about people representing themselves. It is also about consumers representing consumers and carers representing carers. The aim of advocacy is to bring about beneficial outcomes in a way that enables each consumer and carer or group to retain as much control as possible over how it is carried out. The resultant expectation of consumer and carer advocacy is individual and group empowerment.

This Kit is a resource for empowerment of consumers and carers through advocacy. The activities of advocacy incorporate such things as improvement in justice and equity for the individual and/or the peer group, focus on systems and social change (systems advocacy), community development, community education and health professional’s learning.

Advocacy in mental health is often considered to be associated with actions to redress the injustices dealt to people living with a mental illness that result from powerlessness and inequity. This can happen at a very personal level, for instance by people seeking to increase decision making of their own treatment, through to groups of people engaged in major service restructure.

Advocacy is also about seeking to influence the social and political structures that promote and sustain injustice and inequality. The case is put by some that people associated with mental health systems are similar to a range of other disenfranchised groups and that collective radical reform is necessary for positive change to occur.
How is advocacy undertaken?

There are many ways of undertaking advocacy. Consumers and carers can influence how services are provided to them on a day-to-day basis and can look for ways to have their views heard by health professionals. They may participate in the training of health professionals. Some people will be involved in influencing the structure or policies of their local service and so may gain a place on a planning committee or a committee of management or participate in service evaluation. Others will see benefit in trying to influence State/Territory or national structures and gain membership on committees or working parties at this level.

Advocacy, in the first instance, is something that individuals undertake according to their own requirements and expectations. Each person will have a different personal purpose for engaging in advocacy and his or her actions will reflect this. Some will want to act at a local personal level, others at a higher level of influence on matters of national importance.

Increasingly, consumers and some carers are finding opportunities to be employed as paid consultants and to more consistently participate in service design and organisation. (Also see: Some forms of consumer and carer participation.) Some consumer and carer organisations have moved into direct service provision as a way of ensuring that particular needs are adequately met. Some people see community issues as being a particular problem and choose to engage in community education and community development and radical action.

All people feel particularly vulnerable at times and unable to adequately express their needs and requirements. Some may want another person to advocate on their behalf. This form of advocacy is acknowledged in this Kit as a very legitimate form of advocacy, provided the authority of the vulnerable person is accorded the utmost respect at all times.

There is no one way or right way to undertake advocacy. It is something that happens every time a consumer or carer speaks out in support of his or her own cause or that of the peer group. Sometimes the activity is effective and things change for the best, sometimes nothing happens as a result and sometimes it feels like things might have got worse. This Kit aims to provide information that can make some advocacy activities more effective.

No matter how small or personal, every advocacy action is valid and important.
What can advocacy achieve?

There have been many periods of reform associated with mental health services (also see: Consumer and carer movements). Each has built upon the other to improve response to people living with a mental illness, their friends and relatives. More recent reforms have been associated with attention to the rights and responsibilities of people as citizens and movement towards normal community living for consumers as the prime focus. This is an international reform evidenced in many countries and carrying the weight of support of both the United Nations United Nations Resolution on the Protection of Persons with Mental Illness and the Improvements of Mental Health Care (1992) and the World Health Organisation (WHO).

In Australia, reforms have been both supported and driven by the National Mental Health Strategy. This important process, which affects every State and Territory, established many expectations of how consumers and carers should benefit. State and Territory authorities embraced these reforms in varying ways, each incorporating substantial elements of responsiveness to consumer and carer need. There are important messages in the National Mental Health Strategy including the types of policies that are useful, the kinds of services that can be envisaged, the way that health professionals should respond to consumer and carer need and preferred community attitudes to mental illness.

These reforms can only be responsive to consumer and carer need if these needs are expressed in a clear way to those that must hear them. Among consumer and carer rights is the right to be heard and listened to. It is a fundamental expectation that having been heard and listened to, something positive will ensue. Advocacy by consumers and carers is the process by which these expressions are made in anticipation that they are appropriately dealt with. Advocacy challenges services, systems and the broader community to respond genuinely in meeting the expressed requirements of consumers and carers. Without consumer and carer contribution, people will make less than adequate decisions based on other ‘important’ choices.

Advocacy can open doors to participation. It can right wrongs, change the balance of power, address injustice, improve mental health services and alter attitudes and values. It inevitably empowers people in their everyday lives.

Where should advocacy be undertaken?

There is no limit to where advocacy activities can and should be undertaken. It may be in the doctor’s office, the local mental health centre, a hospital, talking among friends and neighbours, through letters to the local paper, through talking to senior managers of health services or politicians, through presentations to health professionals at a university.

Over the years there have been many opportunities for consumers and carers across the nation to state in which areas their advocacy activities are most important. By and large, the message is that concentration of effort is needed on getting the big picture right: on systems advocacy. This means those things like legislation, policies, administration, organisation, systems, attitudes and professional practices. It can then be anticipated that the needs of individuals will be far more readily addressed or, at the very least, easier to negotiate.
Consumers and carers have said that they identify three situations, in particular, where they must have a voice:

- The mental health system and influence on the way services are designed and delivered,
- The higher education system and influence on the way health professionals are educated and trained,
- The broader community and influence on the perceived prejudices that lead to stigmatisation.

**Your rights and responsibilities**

A central statement of support for advocacy activity in mental health is the *Mental Health Statement of Rights and Responsibilities*. This document, produced under the National Mental Health Strategy, has the endorsement of every State and Territory. It describes the rights and responsibilities of all significant participants in the broad mental health system. Specifically, it covers:

- Consumer rights and responsibilities,
- Promotion of mental health,
- Prevention of mental health problems and mental disorders,
- Access,
- Assessment, diagnosis, treatment and rehabilitation,
- Admission to a mental health facility or community program,
- Standards,
- Mental health and legal matters,
- Rights and responsibilities of carers and advocates,
- Service provider rights and responsibilities,
- Community rights and responsibilities.

Carers have expressed concern that the Statement does not go far enough in clarifying their rights and responsibilities.

The Statement spells out an officially endorsed position on what consumers and carers rights are and, therefore, what they should expect from mental health services and the broader community. It also infers substantial opportunities for consumers and carers to promote their rights and to assist in supporting the rights of others.

As expressed in the Statement, rights cannot be considered in isolation from responsibilities. In many cases it is difficult to balance rights and responsibilities. For example, the exercise of one person’s rights without considering the rights of others could mean that he/she gains while another suffers. This is clearly not a good outcome.

Sound advocacy activity incorporates notions of partnership, negotiation and conflict resolution.
Working positively

Consumers and carers have, over the years, expressed considerable discontent with mental health services. Without the expression of some anger, certain reforms may not have been realised as rapidly as they have. This anger has also served as a negative influence on some decision-makers. It has, at times, been interpreted as destructive and divisive. Progress may have been delayed as a result.

Consumers and carers are becoming increasingly organised in the voicing of their respective causes and some people argue that there is opportunity for the anger and frustration to give way to a considered approach to participation and influence. Increasingly, emphasis is being placed on partnership between consumers and carers and in non-tokenistic linkages with service providers, other decision-makers and the broader community. (Also see: Some forms of consumer and carer participation.)

Barriers to effective advocacy

Despite increased awareness and appreciation of the importance of consumer and carer advocacy and the changes that have taken place to enable increased participation, substantial barriers to effective advocacy remain.

Consumers and carers will continue to be challenged by a number of situations including:

- **Lack of credibility** – despite being the experts in the experience of being a consumer or carer, service providers and others will continue to judge themselves as experts in the needs of consumers and carers. Consumers in particular will be judged, because of their mental state, as ‘not fit’ to express a credible voice. Consumers not displaying active symptoms of mental illness, or those who are well into the process of recovery, will be considered unrepresentative of consumers. Both carers and consumers as individuals will be judged as not representing carers and consumers even when invited to participate as a ‘representative’. (Also see: The challenges of advocacy.)

- **Lack of organisation** – sustainability of advocacy activity is increased through organisational support. Advocacy is more effective when the cause is a collective one and when the individual is supported by a strong organisation. While consumer and carer ‘movements’ are growing in Australia, they are not yet sufficiently organised and coordinated for all consumers and carers to benefit from their support. (Also see Engaging networks and organisations and 5.2: Creating networks in Skills, Strategies and Tools.)

- **Resistance to change** – change is difficult to implement. This is particularly true in larger organisations with well-developed cultures. Consumer and carer advocacy is welcomed and, at the same time, is seen as threatening. Calls for change can be met by negative, occasionally subtle and sometimes punitive reactions. (Also see 2.5: Managing change in Skills, Strategies and Tools.)

- **The nature of society** – information and education assists in shaping community attitudes. Information and education will contribute to reducing prejudice but competing pressures will lessen their impact. Only over time will community attitudes move positively towards non-discrimination. Advocacy activities need to match and address both the tendencies of people to discriminate and the prevailing community views held about social justice.
- **Political will** – despite a well-constructed cause and message, advocacy activities may not produce the outcomes sought because of political factors that may not be apparent. Sometimes a good idea is just too challenging at that time or in that situation. Advocacy activities win variable favour at the political level. Support may not be forthcoming because the ideas or the organisation are seen as too ‘radical’. Financial and other support gained to develop advocacy activities may lead to a fear of not ‘biting the hand that feeds you’.

- **Sustainability** – sometimes advocacy activity requires sustained effort. Energy or interest in a cause may not be sustained for a range of reasons. Withdrawing may feel like ‘letting the side down’. New ways may need to be found to ensure support for individuals and to maintain continuity of effort. (Also see 1.1: Looking after yourself and 2.7: Keeping the momentum going in *Skills, Strategies and Tools*.)

Advocacy is not easy at any level. Some of the challenges described are personal ones and can be assisted by good support structures. Most of the challenges are to do with ‘the system’ and often the very things about which change is sought. Even with the best planning and execution there is no guarantee of success.

Remember that inability to achieve what you want is not your fault.

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Some forms of consumer and carer participation

Much advocacy endeavour takes place at the level of survival. Many consumers and carers have little option but to become active in trying to change the way they are being treated by service providers. For some people this forms the essential ‘work’ of their lives, while others are only just learning how to fight for their own rights and/or for the rights of others. In undertaking this primary (personal) advocacy, consumers and carers begin to acquire certain skills such as assertiveness and self-confidence. They learn from experience such things as what language works and gets them what they need; or what sorts of behaviours get people labelled as ‘difficult’, ‘manipulative’, ‘over-involved’. They learn what sorts of approaches have the best chance of getting their concerns taken seriously.

The importance of this kind of personal advocacy is highlighted by an observation made by UK-based consumer activist Jim Read, who says that he has met people who confidently sit on user (consumer) councils but cannot tell you what drugs they are being administered.

The aim of this Kit, however, is to concentrate on those aspects of advocacy which have the greatest capacity to bring about system-wide changes. These resources are aimed at consumers and carers whose participation is driven by the knowledge that they have seen and experienced things they believe need to be changed for the sake of themselves and others like them. A Victorian consumer expressed this well when she noted:

‘In this project we are actually talking about the advocacy that we choose to do rather than the advocacy that we have to do.’

Sara Clarke in Critical Reference Group meeting on 22 October 1997

The levels and nature of participation

Consumers and carers can participate at a number of levels varying in the degree of involvement and responsibility for a project, group or campaign.

Influencing is facilitated through gaining consumer/carer opinion which is then referred to in the process of decision-making.

- At the simplest level this involves making comment – for example, through satisfaction surveys, suggestion boxes, questionnaires, program evaluations.
- A consumer/carer may be invited to participate in some kind of consultation about a specific issue.
Advisory or reference groups (comprised of consumers, carers or both) may be set up to offer input from a consumer or carer perspective.

**Collaboration** involves joint decision-making:
- Consumers and carers are involved in informed joint decision-making with case managers, doctors, and others,
- Consumers participate in consumer groups facilitated by staff, or in short-term consumer-oriented projects,
- Consumer and carer representatives hold full membership and voting rights on decision-making bodies.

**Service delivery** means:
- Consumers/carers form and operate self-help and peer support groups,
- Consumers/carers are involved in lobbying and advocacy activities,
- Consumers/carers are employed to fill roles such as consumer/carer consultancy on projects, consumer/carer liaison in agencies and to conduct social research.

**Consumer and/or carer participation** can occur at the levels of local, regional, State and national agencies and organisations

**Consumers and/or carers** can participate in service delivery, planning, development, policy, training and evaluation

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**Being on a committee/reference group**

**Decision-making committees**

Most committees are formed for the purpose of overseeing a project or completing a task. They are designed for the purpose of making decisions and, therefore, need structure. This structure usually includes a chairperson and a minute secretary (someone designated to take notes). Minutes are an essential record of what has taken place at meetings. All committee members must get a chance to read the minutes before the next meeting. (Also see 3.7: Chairing meetings and 3.10: Note-taking and minute-taking in *Skills, Strategies and Tools*.)

Reading minutes is an easy task for some people because they are eager to see whether the notes taken by somebody else reflect what they remember of the meeting. Others find it a laborious task and sometimes just skip through the minutes before the next meeting (on the bus on the way there!!). Perhaps they read the first paragraph or just glance at the main points.

As with everything, different people develop their own style of operating and, after experimenting a little, find out what suits them best. (Also see 3.8: Being a committee member in *Skills, Strategies and Tools*.).
Working successfully with decision-making committees takes some practice. There are rules about how committees work and, if they intend to participate fully, members need to understand these rules. Consumer and carer organisations often argue that there should be two or more consumers or carers sitting on any committee. This is particularly important where, through their professional or social position, other members have more status and power than individual consumers or carers. There are many publications designed to guide people who are new to ‘committee sitting’, such as *Mastering the Meeting* by J Beaumont.

**Participation in educational forums**

With increasing frequency consumers and carers are being asked to participate as ‘teachers’ in various forms of educational forums. Very often this involves a talk or lecture. People are asked to tell students or professional groups ‘their story’, or to describe, from a consumer or carer point of view, what it feels like to receive services. Consumer organisations and other non government organisations may be asked to run workshops. These may involve working with other consumers and/or carers; or with mixed groups of staff – from clinical settings or, more usually, from the psychiatric disability sector. Workshops may also be organised for the police, school groups or mixed groups in conference settings. While running a workshop may be more effective than giving a talk, it is debatable whether any one-off intervention (no matter how interactive and ingenious) is actually effective in bringing about changes in practice. Consumers and carers may, increasingly, become involved as educators in projects which require a longer term commitment with smaller numbers of staff in practice settings. (For an example of this type of project refer to the section on **Deep Dialogue** on page 34.) Consumers and carers are also being asked to participate in other educational activities: from sitting on curriculum committees through to various forms of student progress evaluation and course design.

**Talking in public**

(Also see 3.2: Telling Stories in *Skills, Strategies and Tools*)

Inviting consumers and carers to ‘come along’ and tell their stories to groups of providers, mixed audiences of other consumers, carers, and providers, school students and others is a practice that has been going on for some time. As consumers and carers have become more experienced in this form of educational work they have realised that the public self-exposure associated with telling stories about painful experiences can be difficult.

Experienced storytellers have developed various techniques and strategies to protect themselves while, at the same time, rendering the storytelling more effective. Since stories are a one-off intervention, it is necessary to make sure that the point of the story stays with audience members long after the event.
Workshop facilitation

(Also see 3.2: Organising Workshops in *Skills, Strategies and Tools*)

A workshop is a more interactive occasion than storytelling. In many ways it involves more careful and strategic planning but less consumer- or carer-centred work on the day. In a workshop the consumers or carers are not the only ones who are required to do work. Workshop participants are obliged to participate actively and are less likely to daydream or avoid engagement. Precisely because of this, some participants might not enjoy the experience: a fact that should be taken into account when a workshop is being evaluated.

Workshop participants may feel a degree of the ‘nakedness’ similar to that experienced by some carers and consumers after a session of storytelling. Some participants might be worried about ‘making a fool of themselves’ and this might lead to subtle forms of resistance. Not all participants will feel like this but workshop convenors must keep it in mind and try not to fall into the trap of ‘rescuing’ people from silences, for example.

The usual model

The most common model of facilitation is one where the facilitator acts as an independent process watcher, arbitrator and note-taker. There are books written and courses designed to teach people facilitation skills.

See Arnold. R in *Educating for Social Change*.

An alternative model

In the book, *Developing Effective Consumer Participation: The Report of the Lemon Tree Learning Project* (pp 58-60), Epstein and Shaw put forward a model of facilitation which is designed specifically for consumers involved in workshops run for service provider staff. The model is designed to challenge assumptions about the inequalities of power between staff and consumers. Although the model is consumer-oriented, its fundamental principles are equally applicable to carers.

In this alternative model, consumer (or carer) facilitators are specifically required to maintain and develop their consumer (or carer) perspective. That is, their task includes conscious interpretation, through their own consumer/carer experience, of what is being said.

Service providers are divided into groups and are asked to discuss issues related to service provision, consumer/carer participation or empowerment. Their observations are ‘recaptured’ for them by the facilitators who draw attention to the way language is used – unconscious bias or disrespect, paternalistic assumptions or slips into jargon, for example.

The facilitators have been taught how to raise consumer (or carer) perspective questions; how to prod participants into thinking from an alternative point of view; how to raise controversial issues and generally how to maintain the power conferred by their status as facilitators.

Anyone organising a workshop should make sure that all facilitators get an adequate opportunity to debrief after the completion of the workshop. Whenever possible this should be in paid time. (Also see 2.1: Briefing and debriefing in *Skills, Strategies and Tools*.)
Simulation games and role-play

Theory
Simulation games and role-play are activities that have met with encouraging results and gained many supporters within the consumer and carer movements. The idea is that participants are encouraged to ‘live’ for a short time through the experiences of consumers and/or carers.

Simulation games may be designed specifically for a mental health audience, or they may be adapted from games used in other areas where there is stigma, powerlessness and a history of misunderstanding and prejudice.

Practice
A simulation game which was originally designed by the Empowerment Center in Boston was enormously successful when it was run by Patricia Deegan, a very well-known consumer activist from the USA, and a team of consumers at the 1996 Mental Health Services Conference (TheMHS Conference) in Brisbane.

Participants were required to wear Walkmans and head phones running taped simulations of ‘voices’. At the same time they were required to perform a quite complicated series of tasks that replicated the kinds of activities provided in a rehabilitation program.

While this was happening consumers played the part of staff and acted out some examples of bad practice including using ridicule, being rude, and treating people like children.

Deep Dialogue forums

Theory
Deep Dialogue is a consumer and/or carer driven alternative to the traditional educational interventions of storytelling and workshops. Deep Dialogue is based on the understanding that what consumers and carers are referring to when they talk about ‘changed practice’ depends upon changes to the service culture of an organisation. This means changes to the values, attitudes and beliefs of service professionals and others.

Any form of cultural change is slow and difficult. It is often resisted. Some politically experienced consumers say that they get tired of having to repeat the same message over and over again. There does not seem to be much evidence of change in practice even when individuals have been affected strongly by hearing someone’s story.
Practice

Deep dialogue provides opportunities for small groups of politically experienced consumers (or carers) and staff from the one unit or workplace to meet regularly. The participants get to know each other as individuals and exchange knowledge and information in a regulated setting. The meetings are facilitated by experienced people so that all participants will feel (and will be) emotionally safe.

The content of discussions is not determined by the organisers. The group decides what they want to talk about as the process develops.

The meetings are held over a period of time, at regular intervals and the membership is fixed. Participants are encouraged to attend all meetings and if someone is away that person is not replaced. This structure is designed to send a message to each participant that he/she is not ‘just another nurse’ or ‘just another consumer’ who can easily be replaced.

The Deep Dialogue process has been successfully trialed at the North-Western Healthcare Network in Melbourne. Detailed information about the trial can be obtained through the Network.

Other examples of interactive learning ideas

Many educators also use interactive activities to break up a session, to warm people up to be responsive and to encourage them to ‘learn by doing’. Sometimes these activities are used at the beginning of a learning session or workshop. They are particularly useful when there is a group of people who do not know each other. A common way of describing these is to use the term ‘icebreakers’. R Arnold, in Educating for Social Change (pp81-112), provides the reader with a varied collection of such activities. These range from group puzzles to stretching exercises (to get the blood flowing!!) and artistic exercises all designed for use by groups or individual educators who are working towards a goal of social change.

At first, inexperienced educators will be wary of involving their students (who may be service providers, secondary school students or the police) in such activities because they may fear making a fool of themselves or ‘forgetting what to do next’. This is common. Most people will need to feel their way the first few times they try to work in this way, but soon it will become easier. It is sometimes hard to picture an interactive activity from reading a textbook. A good idea is for a group of inexperienced educators ‘to muck around’ with the idea or the game on their own before introducing it to others.

Lemon Looning is a board game learning tool for consumer educators to play with mental health service provider staff. This game is available from the Victorian Mental Illness Awareness Council (VMIAC), 23 Weston Street, Brunswick, Victoria, 3056.
Publication of material

(Also see 3.4: Attending conferences and 5.5: Working with the media in Skills, Strategies and Tools)

Some consumers and carers decide that they would prefer to be involved in educational activities through the production of written material. It is possible to learn and develop skills and confidence as a writer (or cartoonist, artist or poet). Courses are usually available through adult education centres, community house programs and so on.

However, writing ability is not enough to get work published by recognised publishing houses. Where you take your manuscript depends on the sort of writing you have been doing. Some work may be published by larger non-government organisations. Your manuscript may be attractive to specialised book publishers such as a feminist publishing house.

Self-publishing

Groups and small organisations often produce newsletters, pamphlets, and so on which include pieces written by consumers and carers. These can be taken along for use in workshops or when storytelling.

Individuals can self-publish material simply by writing, photocopying, and distributing it for a targeted readership.

If you wish to distribute your original work in the public domain, you must remember to copyright it.

To copyright a piece you just have to write your name, the copyright sign, which looks like this ©, and the year somewhere on the article. It is sometimes sensible to include a contact address so that anyone who may want to use the paper can contact you.

Journals

Material that is intended for publication in professional journals must go through a formal process of submission and acceptance. There are many rules about how such a paper is set out and different publications require different types of referencing.

People who are interested in submitting work to a journal could try to contact someone who has had her/his own work published. It may be possible to make such contacts through consumer and carer organisations.

Consumers and carers involved in postgraduate studies in areas related to mental health may be required to publish some of their material. It may be useful if people in this position let a central consumer and/or carer organisation know the publication details. The organisation can then enter the relevant items on its database and direct other interested people to it.

It is important not to become discouraged if your work is refused by a journal. Experienced academics comment that their work might be accepted one time out of 50 or more approaches to various journals.
Conferences
(Also see 3.4: Attending conferences in Skills, Strategies and Tools)
Attending conferences can be very important learning experiences for consumers and carers (as well as for service providers). Participation in a conference may include giving a paper; running a workshop; attending sessions of interest to individual consumers or carers and/or of interest to groups and organisations. Conferences also provide consumers and carers with opportunities to meet people from around the country and possibly from overseas. A conference is, therefore, an opportunity to expand and share knowledge, experiences and understanding about what is taking place in mental health services, in consumer and carer organisations, in various research fields and so on.

Participating in groups
Types of groups
There are many different kind of groups across the mental health area. Perhaps one of the most important reasons consumers and carers join groups is to make contact with other people who have had similar experiences. Social isolation and misunderstanding are harsh and debilitating realities for many people. There is much to be gained through the simple discovery that one is not alone.

There are groups that comprise only a few individuals, and there are groups whose membership runs into the hundreds. The purposes for which groups are formed and maintained are also varied. For example, a small local consumer support group (run for consumers by consumers) can provide much needed social contact, organise day trips and other activities, liaise with the regional services and generally address local consumer concerns. A very large group, such as Schizophrenia Fellowship, is able to address a wider field of issues. As well as providing support, services and information, such a group can lobby politicians and department bureaucrats, and organise State or nationwide public education campaigns.

Between these two extremes are those groups whose core membership may be quite small but who make a point of connecting with other groups – and, where required, helping to establish new groups. For example, VMIAC (the Victorian Mental Illness Awareness Association) is a State specific peak consumer advocacy group which falls into this category. These groups are particularly important because, in addition to their advocacy, general support and coordinating roles, they are able to auspice consumer-headed projects and research such as the Lemon Tree Learning Project.

A useful resource is Joining Together: Group Theory and Group Skills by D Johnson and Y Johnson.
Non-decision-making groups

There are some groups where the emphasis is on increasing understanding between people rather than trying to coordinate campaigns or make weighty decisions. Sometimes people come together in order to share a common interest or to discuss important issues that need to be raised. These sorts of groups are very important in terms of bringing about attitudinal change within services and in the wider community. Such groups may consist of staff, consumers and carers; or they may comprise consumers and carers only. There can also be all consumer groups or all carer groups.

Non-decision-making groups can be the birthplace of ideas. These are the places where the chairperson does not feel obliged to interrupt potentially important discussion and debate in order to direct people back to the task at hand. Ideally these groups are where people (service providers/consumers/carers) come together and feel safe enough to speak about things that never get spoken about during the ordinary business of the working day. They are gatherings where consumers, carers and service providers really get to know each other as people and exchange real human stories.

Topics that have been successfully tackled at such unstructured meetings include: institutionalisation, confidentiality, ‘serious mental illness’, economic rationalism and priority setting, culture carriers for systems change, violence (staff, consumer and carer) and stigma.

Non-decision-making groups are a source of new ideas and understanding as well as sites for open debate and building confidence. However, in many mental health service settings it is very hard to promote intentionally reflective (rather than decision-making) activities. There seems to be little time for people working in this area to think about and discuss issues together. For example, after participating in a deep dialogue forum a nursing staff member remarked ‘I haven’t had an opportunity to talk like this since I was an undergraduate student!’.

For further discussion about these groups, see Understanding and Involvement (U&I) Consumer Evaluation of Acute Psychiatric Hospital Practice: A Project Concludes by M Epstein and Y Wadsworth (pp5-6, 14-17).

Groups on the ‘Net’

With the coming of the Internet and the World Wide Web there are now hundreds of electronic groups and web sites related to mental health issues. There are discussion and chat groups; support groups for people with specific symptoms and diagnoses, support groups for carers and families and others. There are web sites that carry news and information about drugs, about consumer advocacy, about research, and much more. Many consumers and carers across the world are now able to make contact and share information quickly and easily by means of e-mail.

Clearly not everyone has the resources to own a computer and pay for an Internet Service Provider account, but provision increasingly is being made to enable more consumers to ‘get on line’ – ask at your local public library.

For further information see Developing Effective Consumer Participation in Mental Health Services: The Report of the Lemon Tree Learning Project by M Epstein and J Shaw (pp65-69).
Paid work in the mental health field

There is a new environment in the mental health sector. Consumer and carer participation and involvement in service delivery, policy direction, service evaluation and educational experiences for staff is being sought. This is providing increased opportunities for those with ‘expert’ consumer/carer experience to become involved as employees and consultants. Sitting on committees; evaluating services; giving ‘expert’ advice to policy writers; proofreading documents from a consumer or carer perspective; sitting on employment interviewing panels; running education activities is work. A fundamental of self advocacy activity is to ensure that those involved in such work are adequately resourced and well paid.

Salaried staff

Example one: staff-consumer consultants

Staff-consumer consultants are employed by hospitals and Area Mental Health Services. Their purpose is to involve consumers in collaboration with staff in regularly reviewing and improving the quality of services. The activities of staff-consumer consultants include attending regular community ward meetings and programs; facilitating consumer only meetings; establishing and maintaining consumer networks and consumer consultancy groups; facilitating staff/consumer dialogue forums; being involved in and facilitating consumer representation on management and program committees, quality assurance activities and policy development.

Staff-consumer consultants are not members of the treatment team or therapeutic staff; neither are they individual consumer advocates or buddies – they are systems advocates. The word ‘consultant’ has been used in their title simply to indicate that knowledge of the lived experience of mental illness is a special expertise which they bring to the workplace. (Also see 3.9: Being the ‘layperson’ among ‘experts’ in Skills, Strategies and Tools.)

Example of systems advocacy

Mahara is employed by a service as a staff-consumer consultant. She has a long history of living with mental illness so she has expert knowledge and a strong commitment to a consumer point of view. One day she is working on the Acute Unit. Mr Jansen comes up to her. He trusts her just a little bit because he knows she has also been a patient. Mr Jansen is angry because the doctor had said that she would speak to him that morning and it is now 3.00pm. No one has spoken with Mr Jansen to reassure him that the doctor will see him at some other time, or to explain the doctor’s failure to see him at the arranged time. Mr Jansen feels that no one will listen to his concerns.

Mahara is angry and concerned about the way that Mr Jansen has been treated and she feels a bit guilty that her job is not to go and negotiate with staff on his behalf. She asks him if he has spoken to other staff members. She also directs him to the notice board where he can find the phone numbers for Community Visitors who are individual advocates and who can, perhaps, complain on his behalf.

Example of systems advocacy continues on next page
Mr Jansen is not the first inpatient to have complained about doctors not keeping appointments. Mahara checks her journal where she has jotted down previous complaints of this nature: there have been three in the past two weeks. She decides to take this matter to the next Community Ward meeting and ask the inpatients who are present whether anyone else is having this problem. She will note any examples that are given and see if anyone has any suggestions about how this problem might be addressed. After this meeting she might have more information and be in a better position to meet with the unit manager and the doctors with a request to seek a solution as quickly as possible.

The go-between: are you staff or are you consumer/carer?
When a consumer or a carer becomes an employee of any service or agency which provides services for consumers, difficulties can arise. It can be confusing wearing two hats at the same time. Anyone who is thinking of applying for a position as consumer/carer representative or consumer/carer consultant needs to think carefully about her/his primary responsibility as a consumer or a carer.

People who are employed within the system as consumers (or carers) need to seek clarification of the extent to which they are accountable to management and the extent to which they are accountable to consumers who use the service.

What happens if there is conflict between these obligations? Consumer/carer staff members need to be well informed regarding what processes are in place to protect, advise, and support them should this type of conflict arise. (Also see 2.3: Dealing with conflict of interest in Skills, Strategies and Tools.)

Wearing two hats: what is a consumer or a carer perspective?
If, as a consumer or carer, you are employed by a service as a consultant or representative, then you are there because you have had experience as a consumer or a carer or both. It is expected and understood that your perspective will be coloured by your personal experience as a recipient of services. Most people wear more than one hat and fill more than one role in their lives. In working as a consumer/carer consultant or representative it is particularly important that you remain aware of your multiple roles and of the biases that come with them. Try to be sensitive to the differences in the perspective and experience of consumers and carers with whom you come in contact.

A ‘consumer perspective’ evolves from the experience of seeing the world through the eyes of someone who has at some time been categorised as ‘mad’ or ‘distressed’. A ‘carer perspective’ arises through sharing a close and empathic relationship with one or more ‘mad’ or ‘distressed’ individuals. Many people have had such experiences but it is a matter of choice whether or not someone identifies him/herself in terms of these experiences. Although self-identification is not necessary for someone to say that they have a consumer or carer perspective, it can be argued that it is necessary for those who choose to participate in consumer/carer politics.
Issues and debate

There is some debate about whether an employee of a service is able to critically examine that service at all. It has been suggested that people appointed as staff-consumer consultants have no real power or authority; that their job requirements may be impossible; and that such positions have been created more for political reasons than for improving the quality of the services.

Leading up to the employment of the first four staff-consumer consultants in Victoria, a major piece of research was undertaken by the Understanding and Involvement (U&I) team (Orientation and Job Manual: Staff-Consumer Consultants in Mental Health Services by Y Wadsworth and M Epstein [1996]). This research identified a need for consumer staff to be employed within services. The staff-consumer presence (according to the U&I research) would encourage the development of more sensitive direct feedback for the benefit of clients of the services, leading to an improvement in service quality. The staff-consumer consultant positions were not designed for the purposes of individual advocacy activities. Rather, the intention was to make the positions part of the fabric of service delivery, accepted by both staff and consumers as part of the taken-for-granted workforce.

Example two: consumers and/or carers employed by non-government organisations

The employment of carers and (sometimes) consumers by non-government organisations (NGOs) has been far more common than their employment by services. Most often they have worked as lobbyists or advocates whose force and authority derives from their independence from the service system.
**Issues and debate**

The actual independence of non-government organisations is sometimes challenged by those who argue that, while they rely on government funding, NGOs cannot be fully independent of elected governments and departmental bureaucracies.

**Example three: consumer advocates in the hospital setting**

This particular form of advocacy involves consumer-staff members being employed to carry out a variety of important activities. These include providing information and support to patients on an individual basis; letting patients know about their rights and responsibilities; giving assistance with resolution of grievances and complaints and working with mental health professionals to address patients’ concerns about their treatment and the services provided.

Consumer advocacy in the hospital setting is operated successfully by the Rozelle Hospital Consumer Consultants Service.

**Freelance consumer and carer consultants**

In Melbourne a group has been formed called the Melbourne Consumer Consultants’ Group. The group’s membership includes consumers who are working either as freelance consultants or as salaried staff. They meet regularly to record their increasing knowledge and understanding, to compare tactics, to debrief and to replenish and gain strength.

The group has recently published a book called, *Do You Mind? The Ultimate Exit Survey: Survivors of Psychiatric Services Speak Out*. The book includes discussion of issues such as stigma, empowerment and self-help, interpersonal communication, complaints systems, police involvement, medication, discharge planning and rehabilitation. Similar groups are likely to spring up around Australia.

There are many carers and consumers who are engaged in freelance consultancy work all over the country. This example of freelance consumer consultants forming a mutual support and information exchange group, however, is the only one of its kind (so far) in Australia. (Also see 1.8: The business end of participation in *Skills, Strategies and Tools*.)
Being a volunteer

Why be a volunteer?

There are many reasons why people choose to contribute to society as volunteers rather than (or as well) as paid workers. As well as benefiting others, volunteering is also ‘good for the volunteer’. Some of the reasons why people volunteer have been listed in an American journal, *Voluntary Action Leadership*:

- helping others
- gaining work experience
- learning new skills
- changing the status quo
- meeting new people
- testing a new career
- gaining academic credit
- building self-confidence
- putting a hobby to good use
- learning responsibility
- being a winner
- gaining recognition
- putting faith into action
- preserving the past
- getting to know prospective clients
- being an individual not a number
- meeting those with similar values
- giving back what you’ve got
- improving the community
- utilising untapped educational skills
- getting out of the house
- staying active and involved
- being needed
- making professional contacts
- experiencing different lifestyles
- doing satisfying work
- meeting new challenges
- fulfilling a tradition
- sharing fun time with family & friends
- using natural gifts/talents
- helping a friend
- influencing others
- searching for a job
- empowering others
- being a role model for children
- showing that you care
As a volunteer you have the **right** to:

- Information about the organisation for which you are volunteering,
- A clearly written job description,
- Know to whom you are accountable,
- Support and supervision in your role,
- A healthy and safe work environment,
- Be covered by insurance,
- Say ‘no’ if you feel that you are being exploited,
- Be reimbursed for out-of-pocket expenses,
- Be advised of the organisation’s travel reimbursement policy,
- Be informed and consulted about matters which directly or indirectly affect you and your work,
- Be made aware of the grievance procedure within the organisation,
- Orientation and training.

As a volunteer you have the **responsibility** to:

- Be reliable,
- Respect confidentiality,
- Carry out the specified job description,
- Be accountable,
- Be committed to the organisation,
- Undertake training as requested,
- Ask for support when you need it,
- Give notice before you leave the organisation,
- Value and support other team members,
- Carry out work you have agreed to do responsibly and ethically.

**Interviews** conducted to select volunteers are very similar to job interviews. Remember that it is **important to ask questions as well as to answer them**. You may want to know more about your responsibilities; about the structure of the organisation; about training programs and so on.

You should be prepared to answer questions about previous work experience; skills, qualifications and interests. You should also be able to supply names of referees.

There are Volunteer Centres in all Australian States and Territories, for example Volunteering ACT Inc; Volunteering NT Inc; Volunteering NSW Inc; Volunteering WA Inc.
‘Radicals do not seek to introduce politics to an apolitical situation. Rather we mean to challenge the politics of compliance and to introduce the politics of resistance and change.’ Galper 1980: 11

Taking action to influence the social/political system or being an activist means many different things to many different people. There is no precise or prescriptive definition of social/political action; there is no one method of bringing about change. Each person who works for social, cultural, political change is an activist.

Some fundamental understanding about social/political action
Those who are affected by (or who have identified with) an issue are in the best position to understand and define the problems and, subsequently, to determine potential solutions.
Change will come about through people working in many and various ways towards the same ends.
Individual action can bring about change and can inspire others to take action.
Successful action depends on solidarity and strength of conviction. You need to hold a strong belief in the truth of your demands.
Individual action should not mean that those working for change have to do it in isolation.
In order to take social/political action you need to believe that change is necessary and possible.
In Australia and throughout the world there is a long history of successful activism and so a lot of practical experience to draw upon. At times you may feel disheartened because changes have been insufficient – so much more needs to be done. However much of the change that has been achieved in areas such as the environment, civil rights, equal opportunity, freedom of speech and mental health would not have happened without political and social activism in communities and outside of governments.

It is people power, individual actions and group campaigns that have brought about changes to society.

Carers and consumers are often motivated to become involved in actions, campaigns, groups, forums and various government initiatives because they want to improve things in the mental health system. For some people the way to ‘improve things’ is to participate in advisory groups or contribute as consultants; that is, to work within the system. For others the way to ‘improve things’ is to work outside the system and outside formal processes of governments. These people choose to take action and organise or join campaigns against injustices to highlight the desperate need for change.

How to take action

‘To bring about social change people have to take action as individuals and as groups. Bringing about changes will require a lot of individuals taking action on many levels; but to do so requires a belief that you as an individual, and the individuals around you, can make a difference.’ Shields, 1993

You can make a difference by exercising your consumer choice; by the quality of your relationships with friends and neighbours; by writing to your local member; by organising a petition; by taking part in campaigns, rallies and demonstrations. You can also write letters to newspapers; ring up talk back radio; and speak out against injustices.

It is important that you believe you can make a difference - and you can:

‘It is from taking action that the fear and powerlessness begin to transform themselves’ (Shields, p7). Change is possible and often it starts with one person or a small group of people taking action and speaking out.

Small beginnings and individual actions have been a feature of bringing about improvement in mental health services and in changing public perceptions about ‘mental illness’. (Also see: Consumer and carer movements.)

Before taking action you need to decide what you can realistically achieve either as one person or as a group. Many potentially effective actions do not require huge numbers of people. One person writing to their local member, writing to the newspapers or collecting signatures on a petition can achieve much. A small group of people can successfully organise brilliant symbolic actions which gain broad media coverage for the issue of concern.
Tips for organising

- Think about how many people are prepared to do something and what skills you have between you, such as writing letters, speaking to groups, singing, street theatre, talking to the media, etc.
- What are you interested in doing? – speaking, writing letters, participating in rallies, making banners?
- What do you need in order to feel safe? – working with others, knowing your legal rights, having a buddy?
- Before you become involved in action it is crucial to know your own limits - think carefully about how far you personally are prepared to go, and about what role you want to take in any action.
  - Are you prepared to be quoted in the media?
  - Are you prepared to have your photo/picture appear in the media?
  - Are you prepared to disobey authorities?
  - Are you prepared to get arrested?

Some of these considerations are particularly important for consumers and carers in the mental health area because of the shocking stigma which still exists in the community. **No one should ever be made to feel that they must get involved, especially if they believe that their involvement may affect their lives adversely.**

- On a practical level you might need to get legal advice – think about whether you need a lawyer present at a direct action.
- Feel empowered: taking personal action is a practical way to challenge laws or actions that you consider to be unjust. Speak out and communicate with those involved. Question what the authorities say and propose alternatives.
- You do not have to act alone or work everything out by yourself. Speak to other people who have had experience in political actions and get their help and ideas – network across different causes and issues.
- Know your own strengths and limitations – always work from your strengths and in a way that you feel comfortable.
- Take care of yourself and others working with you – take the time to ensure that everyone is comfortable and committed to any action planned.
Involvement in research

Consumers and carers are often asked to be involved as subjects in research. Usually this research has been designed and will be carried out by academics and professional researchers. Less commonly, small pieces of research are undertaken by practitioners (doctors, psychiatrists, psychologists, social workers and others). Occasionally researchers enlist the paid or unpaid assistance of consumers and carers in the collection of data or interpretation of its meaning. In recent years national policy has led to an increase in this ‘inclusive’ practice in the case of government-funded research.
As a subject

The word ‘subject’ is less frequently used these days. It is thought that it gave an impression that a research participant was being experimented on. Unfortunately for some consumers it is only the word ‘subject’ that has changed. For many consumers, the experience of research remains essentially one of being disempowered. Data is extracted from them: they are given little chance to tell their own story, to give the answers to the questions they want asked, to give meaning to their own data or even to be given feedback about results.

On a research or ethics committee

As the push by consumers and carers to participate in service delivery, policy, evaluation, and research continues, there have been moves towards including a category of consumer/carer in the designated seats of institutional Ethics and Research Committees. All research which is carried out under the auspices of, or with subjects from, any service must be assessed by both of these committees. Experienced researchers talk about ‘getting through’ the Ethics Committee or ‘getting through’ the Research Committee.

Traditionally such committees (Ethics and Research) have included seats for senior practitioners; ‘experts’ both in law and in medicine; important community figures representing a ‘lay’ position; clergy and other co-opted members from the service community.

Up until recent years, the thought of including consumers and carers on such committees was inconceivable. This situation is now changing as it becomes clearer that lawyers, doctors and clergy may have different ethical positions to their clients, patients and laity.

The role of carers or consumers on such committees may well be a tricky one. They might have to be quite assertive about researchers describing their projects in ways that are understandable; and in asking that abbreviations, acronyms and jargon are carefully explained. This kind of role can be daunting for politically inexperienced people. The consumer or carer member may work out a set of research requirements that they ask about routinely.

A consumer or carer member of a research or ethics committee may put forward suggestions for good practice, for example:

‘I see that you are intending to give the X, Y or Z test to consumers in this project. How do you intend to get informed consent? I would like to see you employ consumers to explain the research to all potential subjects before informed consent is sought. Could this be written into the research design?’

It is possible that where the consumer or carer is in the minority, such a suggestion might fail to be carried by the committee. Nevertheless, the very fact of having it raised routinely will have the effect of influencing other committee members. Eventually these kinds of concerns will infiltrate the research community. Researchers will begin to anticipate them and will think about the implications before they submit their proposals.
As the researcher

Many people are scared of the word ‘research’. Somehow they envisage research as something only scientists can do: something that has a frightening mystique; that requires advanced skills in statistical analysis; as something which only professional researchers can do. This fear of research seems to hold true for some front-line practitioners, as well as the majority of carers and consumers.

Consumers and carers are becoming increasingly dissatisfied with research that seems to be asking the ‘wrong’ questions. Slowly consumers (and carers) are realising that they already have many of the skills required to undertake grounded research projects.

**Research ideas that come out of the interests of consumers and carers will have a different emphasis.**

Amongst professional researchers, consumers and carers are increasingly being seen as co-researchers. Some consumer bodies have reversed the roles and now conduct their own research: inviting non consumer researchers to act as facilitators or design consultants.

As an evaluator

Increasingly consumers and carers will be asked to participate in evaluation exercises. These exercises will sometimes (but not always) involve the work of independent outsiders whose methods require them to work with local consumer and carer communities in developing an evaluation design. Increasingly consumer consultants will be asked to contribute to such designs. If consumers and carers are unfamiliar with current debates within the research and evaluation communities, they may feel intimidated by the language and process. They may also feel that they are under pressure to support something which – on paper at least – looks like ‘science’.

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The challenges of advocacy

Advocacy can lead to opportunities for self-empowerment and personal fulfillment. The effectiveness of a person’s advocacy activities can be increased through acquiring knowledge, clarifying attitudes and values, and learning specific skills and strategies. Many of these points are outlined in this Kit. At every turn, advocacy presents to the consumer or carer both opportunities and challenges. The challenges may be minor hurdles that can be addressed with basic skills; or they may be major issues requiring greater expertise, experience and organisational support.

This section provides an overview of some of the major challenges of advocacy in mental health. These are:

- The ethics of advocacy,
- Representation,
- Accountability and responsibility,
- Tokenism,
- Participation as ‘therapy’,
- Being prepared,
- Being valued,
- Facing extra challenges,
- Dealing with organisational culture,
- Dealing with the bureaucracy,
- Dealing with the politics,
- Dealing with legislation.

The ethics of advocacy

Within a general community certain behaviours are considered either acceptable or unacceptable. The way that a particular behaviour is perceived, and either accepted or rejected, may differ markedly between the various groups that make up the community. Group ethics will not always be the same as broader community ethics.

Many of the sanctions (positive and negative) that support community ethics are informal, but some are formalised in legislation and maintained by social institutions such as the police and the law courts. Some professional groups have special ethical codes that prescribe correct and responsible conduct. For example, nurses, teachers, lawyers and others are expected to follow strict guidelines setting out appropriate professional behaviours for general and particular situations. Some consumers and carers have been critical of certain aspects of professional codes of ethics or, rather, of the way that these are interpreted and used in the mental health system.
An ethical framework for advocacy

Since advocacy is directed fundamentally towards issues of justice and equity, consumer and carer advocacy activities are strongly underpinned by ethical understanding. Advocacy is about consumers and carers being valued as equal citizens. It is about empowerment. If there is a ‘code of ethics’ for consumers and carers, it is based on a platform of human rights. Some consumer groups, in particular, have begun to define this ethical framework through the creation of ‘bills of rights’.

In the context of the Australian mental health system, the *Mental Health Statement of Rights and Responsibilities* developed within the National Mental Health Strategy, acknowledges the importance of the contribution of consumers and carers at all levels of mental health policy and service provision. This document has important implications for consumer and carer advocacy. It provides an officially sanctioned ethical framework within which advocacy can be conducted. It implies that it is ethically appropriate to pursue rights, equity and justice as expressed in the Statement. While consumers and carers may debate the relative worth of the Statement in the ‘real world’, its recognition of the right to pursue issues of justice and equity is an important contribution to consumer and carer advocacy.

Some consumers and carers argue that the Statement does not go far enough in recognising the entrenched inequities of power distribution in society as the basis of injustice in mental health. It is possible that the Statement will be further developed on the basis of lessons learned from increasingly empowered consumers and carers. The issue of whether self-empowerment succeeds from revolution or evolution is an ongoing consideration for consumers and carers, as well as for other disenfranchised groups.

A few basic perceptions about rights and responsibilities are worth noting:

- Rights are not the special entitlement of the few. Everybody has a right to be listened to. This does not mean that everyone should have the same views and opinions but, rather, that people’s views and opinions – especially about their own lives – should be treated with respect. This is a right often ignored by those in positions of power. It is a right frequently denied in certain relationships, including those between service providers and consumers or carers, and those between consumers and carers.

- In seeking to reclaim basic rights, some people pursue them vigorously. There are times when this is necessary. Excessive vigour is sometimes interpreted as ‘aggression’ and can lead to antagonistic responses. This can be because the rights of one person conflict with those of another. More often, however, there is a lack of understanding and/or a fear of change at the root of antagonistic responses.

- Rights go hand in hand with responsibilities. Among the rights that consumers and carers are most concerned with is the right to be responsible. As with all ethical matters, the question of what constitutes responsible behaviour is subject to many interpretations. At the same time, suggestions that basic human rights can be denied to those who fail to measure up to someone else’s notion of responsibility are quite unjustifiable. The whole point about rights is that they are fundamental and unconditional entitlements.
Social justice

Consumers of mental health services are traditionally considered vulnerable at certain times and requiring special legislation or policy to ensure their protection. Providing additional protection within a context of social justice is an ethical principle applied particularly to consumers of mental health services. Depending on the circumstances, additional protection may offer consumers greater opportunities for empowerment, or it may grossly disempower them.

Social justice is grounded in the notion that people have rights and that everyone’s rights need to be considered and taken into account. The worst examples of infringement of rights should be addressed as a matter of importance. Sometimes balancing the rights of different people is a very difficult exercise. However, the difficulties involved are often amenable to negotiation, education and mediation. Insoluble difficulties can be drummed up as an excuse for a failure to pursue social justice issues.

Even with the weight of legislation and policy behind the pursuit of rights, there will be those who do not recognise the essential principle of equal opportunity. There will often be some disagreement about priorities: which rights are more important to pursue for which group at what time. Some individuals and institutions will find it difficult or even impossible to accept or understand advocacy activities and may create obstacles to this kind of activity.

Confidentiality

Confidentiality is about consumers and carers having control over who has access to information about them and in what form.

There are many issues around confidentiality and they are neither as straightforward or as obvious as they might, at first, appear.

- Consumers’ and carers’ understanding of confidentiality is not necessarily identical. What consumers and/or carers mean by confidentiality is also likely to be quite different from what service providers mean.
- Confidentiality means that information, given in the belief that it will go no further, is not discussed with others.
- Confidentiality means that you do not identify a person to a third party (or parties) without that person’s permission – and their clear understanding of how, where, and to whom identification will occur.
- Confidentiality means that you do not discuss another person’s affairs where you could be overheard by those not directly concerned, for example, in hospital corridors.
- Confidentiality means treating any information you have about another person with respect for their privacy.
- Confidentiality does not mean that when quoting a consumer or carer you should routinely render your source anonymous or reduce her/him to a first name only. This is stigmatising and disrespectful if you have not consulted the person. Consumers have different needs and experiences. Some consumers are proud of their ‘loony’
status and want more than anything to be listened to, to be heard and to be acknowledged. If you are intending to print or publish material written by a consumer or which mentions a consumer, always ask how he/she would like to be acknowledged. DO NOT assume that they will be embarrassed and ashamed about their name being used.

- Confidentiality does not mean withholding relevant information from another person or persons under the guise of professional behaviour.
- Confidentiality does not mean discussing the affairs of someone you are representing in confidence with everyone except that person.

Representation

Consumer and carer advocacy can be about putting a personal view or, occasionally, the view of another individual. Sometimes it is about putting the view of a group, organisation or network.

Advocacy incorporates the notion of consumer or carer ‘representative’; that is, of people who are asked to ‘represent’ a group or a cause. Being clear about the intent or purpose of representation, from the point of view of the person or group making the request, is important. Are you being asked to represent your own views as an individual; the views of a particular group of consumers or carers or the views of an organisation with which you are associated? Perhaps you are not really being asked to represent anything but, rather, just to be there so that people can say they have included consumer or carer representation.

People who are asked to represent a group must take care not to assume that they know what the group wants them to say. Any such careless assumption can easily lead to misrepresentation of the group interests. Consumer and carer representatives can create processes for consultation with other group members to ensure that the consensus position is represented as fairly and honestly as possible.

Just as the representative has a responsibility to her/his group, the group has a responsibility towards its representative. Representatives require active support from those they represent. Members of the group can assist by being prepared to participate in consultation and to make their views known.

It is unfortunate that debates regarding the limitations attached to consumer and carer participation are often based on arguments about a person’s capacity to represent a group or constituency. Such arguments never seem to arise in the context of representing provider groups, administrators or others.

When people do not say what somebody else wants to hear, one of the most common ways of negating their contributions is to accuse them of not being representative.
The challenges of advocacy

Sometimes a person is denounced as a ‘professional’ consumer or a ‘professional’ carer. These terms are used to cast doubt on that person’s legitimacy as a consumer or carer. Carers have found that this derogatory label is frequently applied to those who do not actually share a house with a person living with mental illness. These are individuals who nevertheless see themselves as ‘carers’ and who believe that they have important perceptions to share with service providers and/or the community. Many consumers, as they become more politically experienced and more confident, have found themselves accused of being ‘professional’ consumers. Sometimes the accusation is made directly but, more often, it is said behind people’s backs.

Unfortunately this sort of put-down sometimes comes from within the consumer and carer groups themselves.

People who have been tempted to criticise others by using this type of language might find it useful to question their own motives. In that way they can discover the real issues behind their anger. Consumers and carers who know that they may be targets for this type of criticism can consider the following:

- Think of a response that does not involve you in a power struggle if directly confronted. Some people just reply: ‘Yes, I pride myself on my professionalism. Thank you.’ They deflect the intended insult by deliberately misunderstanding it. They take the word ‘professional’ to mean organised, diligent, ethical, experienced. Of course, many consumers or carers working in ‘the system’ would want to be described as ‘professional’ in this way.

- Explore your own presentation as consumer or carer. Do you come across as a ‘know-it-all’ or as being arrogant? Do you ‘hog the floor’ at meetings? If you are representing others, do you consult with them? Do you take questions back to your group? It might be that you need to modify the way you present yourself.

It is important that politically experienced consumers and carers make themselves available to others so that the skills can be passed on. This is the way, for instance, that psychiatrists are trained. Medical school graduates are supervised (or mentored) by experienced practitioners before they are admitted to the College of Psychiatrists. Formal arrangements are in place to implement this model in psychiatry. Although consumer and carer organisations do not have the guidance of formal accreditation procedures, they can benefit from maximising opportunities for more people to gain experience and confidence in different kinds of participation.
Other people sometimes see consumers and carers as representing a collective opinion even when they are not formal representatives. Some experiences of consumers or carers are collective. They speak informally with their peers and gather a wealth of information that helps to broaden their consumer or carer perspective. Despite this common ground there are also very different experiences across the consumer and/or carer communities and respect for differences is a central proposition for effective advocacy.

The word ‘representative’ or ‘rep’ is often used carelessly to describe people who are not, and were never meant to be, representative of any constituency. For example, someone might say: ‘Oh, you mean Sandy! I think she’s the consumer rep on that committee’. More attention to detail would reveal that Sandy is in fact a member of that committee and holds a position that is reserved for someone who is a consumer. This is very different from being a representative.

The challenge in advocacy is to maintain a strong sense of the collective (shared) consumer or carer perspective, while being respectful and sensitive to individual and minority differences. One way to stay in touch is to be part of a consumer or carer organisation where views are exchanged regularly and where individuals can remain constantly aware of the broad thrust of collective opinion. It is also useful to refer to the increasing number of consumer and carer publications: books, participation kits, pamphlets, newsletters and others. Sensitivity to differences within the consumer or carer movements can be developed by listening to as many people as possible, whether these individuals are members of a group or not. It is particularly important to consider the views of ethnic minorities, women, gay and lesbian consumers and carers and elderly people (consumer and carer). Without this attention to difference, the ideal of increasing consumer and carer participation and self-determination becomes impoverished and elitist.

**Accountability and responsibility**

Each person is accountable to him/herself and to others who may be affected by his/her words and actions or, for that matter, by his/her silences and inaction. Being accountable means that you need to be able to justify your words and actions in a given context. You need to be able to give an account of what you did and why.

In some cases you may be required to be formally accountable to an employer, funding body, group, or person (for such things as reports, invoices). In other cases, accountability may mean taking responsibility for your role in a less formal or structured way.

You may find yourself in a situation where you are accountable to more than one person or group. For example, if you are a consumer or carer representative on a committee, you may be accountable to the committee itself and a public or private funding body, as well as to the people (consumers, carers) you are there to represent. If, for some reason, the interests of the three groups do not coincide, then your primary accountability is to the group, person, or persons that you represent.
Examples

1. A consumer is elected to represent a group on a government committee. Some of this work involves material that the government wishes to remain confidential. The consumer is told not to tell anyone, including members of the group she is representing.
   - To whom is the consumer accountable?
   - How could the consumer resolve this dilemma?

2. A carer is nominated to fill a vacant position on a project advisory committee. He knows that he is there because he has had a lot of experience in various carer organisations. However, he has not been asked on to this committee as a representative of any of these organisations.
   - To whom is this carer accountable?
   - Can he ask another carer (or carers) for an opinion on a difficult issue?

In both examples you are accountable to yourself. You need to believe that you have acted correctly and according to your own understanding of your role, values and ethics.

Tokenism

Tokenism is the convenient inclusion of a representative from a socially marginalised group into a mainstream body. Tokenistic appointments are frequently made to fall in with anti-discriminatory legislation or to take advantage of targeted funding opportunities. Token inclusion of consumers or carers as researchers, as institution staff, on advisory and evaluation boards and in other situations are not genuine attempts to listen and learn from the ‘other’. They are, rather, ways of avoiding such genuine attempts. Even legitimate attempts to include a consumer or carer perspective in the planning and delivery of services run the risk of tokenism. This is due to the way in which consumers and carers are seen within the services that they use.

Tokenism is one of the major difficulties facing consumers and carers who work within the mental health system. Various consumer and carer organisations around the world have suggested ways in which the problem can be addressed.

Ideally there should be at least two (preferably more) consumer/carer representatives or employees, especially in those situations where the majority of participants are mental health professionals who might be expected to share similar opinions. A lone consumer or carer in such situations risks becoming no more than a token presence, no matter how articulate and committed to change he/she is.

Nevertheless, the danger of tokenism is ‘not averted simply by ... (including) two, or three or four (consumers/carers)... The concern is not just about numbers but about how (consumers/carers) are treated and which decisions they can make’. (M Hutchinson and T Ausland)
Too often consumers and carers are consulted to ‘okay’ predetermined decisions with little or no opportunity to contribute to the decision-making process. Clear, understandable information must be available to all participants, and the importance of the decisions consumers and carers can make must move from the cosmetic to issues that might matter more.

Consumer/carer participation cannot successfully be tacked onto existing structures. This practice can be seen in many provider education and training courses that include a consumer- or carer-run presentation. This vital contribution is all too often added at the tail-end of the program, as an afterthought and a one-off. Once again this minimises consumer/carer input. In fact it further marginalises the consumer or carer perspective.

If consumers and/or carers are included during the planning stages of programs in which they are to participate, this problem can be avoided. Another way in which tokenism can be avoided is to ‘...give participation (in projects, meetings, etc) a high profile and a clearly positive image. Don’t let consultation activities slip in through the back door with only a few people knowing anything about it’. (M Hutchinson and T Ausland)

**Participation as ‘therapy’**

One of the assumptions sometimes found among people working in the psychiatric sector is that participation is somehow ‘good’ for consumers.

Many consumers and carers can acknowledge that they have learnt much through participating in committees, education, research and other activities. Successes in public speaking, chairing committees, sitting on advisory groups or interviewing applicants for jobs may well lead to individuals feeling more empowered, more confident and happier with their lives. Nevertheless, the assumption that this is the reason consumers and carers choose to participate is mistaken and counter-productive.

Such an assumption:

- Undermines and devalues the participation of consumers and carers driven by their recognition of a need for improvements to the services they use – these participants are vitally concerned with making sure that others will receive a better standard of care;
- Undermines the reality that many forms of participation are very, very difficult and place heavy demands on consumers and carers – systems advocacy, for example, is extraordinarily difficult in any setting because, inevitably, it is resisted and opposed by people who support the status quo;
- Casts consumers – yet again – as the ‘takers’ (of activities designed to make them better, more confident, better organised) rather than as the ‘givers’ (of advice, of education for improved practice, of expert opinion). This is intrinsically disempowering. Again consumers are being asked to carry all the ‘illness’ (dysfunction, ineptitude, lack) while service providers carry all the ‘wellness’ (function, skills, knowledge). It needs to be remembered that service providers do not necessarily have the skills and knowledge required to sit on a committee, conduct workshops and so on.
Being prepared

Undertaking advocacy activities has its risks for individuals. The act of putting forward a position in an attempt to produce change or to maintain the impetus of important things that are happening also means putting yourself forward. Even when acting with or on behalf of a group, advocacy is still a very personal event. Giving of yourself in this way means personally feeling good about the gains that are made. It also means feeling disappointed, frustrated and even hurt when things do not go so well.

Assessing the risks both to yourself and to the effectiveness of the message you are delivering is important. Being well prepared and organised is a good way of reducing the risk of being ineffective and of minimising stress. It is also useful to take account of your personal resources, recognise personal boundaries, take care of yourself and work through your motives for being involved.

Judging your preparedness to expose yourself to the risk of disappointment, perhaps through hearing stories told by others, is another way of reducing risk. If you feel particularly vulnerable it may be better to postpone an opportunity than to proceed with it. However, the risk may be worthwhile; only you can decide. Having people around to provide support when things are not going so well, or to join you in celebration of success, can prove invaluable.

Being prepared is about getting organised; maybe sorting out some routines and managing commitments. It is about creating networks, finding people to undertake advocacy activities with, creating opportunities for debriefing, sharing ideas and information. It is also about developing new skills, increasing your knowledge about the things around you and being open to new opportunities.

Being valued

Consumers and carers have a wealth of experience, wisdom, knowledge and skills that can be used to have an impact upon mental health systems and the broader community. Experience, to date, for most consumers and carers, is that these capabilities are seriously undervalued, especially within mental health service structures.

Relationships between consumers/carers and service providers are invariably unequal: doctor/patient, provider/recipient, well/ill and so on. There are very few examples of genuine partnership. Continued advocacy activity needs to be directed towards shifting the balance of power.

Traditional power relationships make it very difficult for consumers and carers to be valued as equals when they engage in advocacy activities. The challenge for consumers and carers is to engage in ways that will increase recognition of their value. Valuing oneself is important but, sometimes, this is particularly difficult to achieve or maintain. Opportunities for demonstrating knowledge, skills and confidence will increase feelings of self-worth. This will also encourage detractors to modify or change their attitudes. Pursuing symbolic recognition of value, like equitable financial reward for participation is also important.
Facing extra challenges in rural communities

People living with mental illness in rural communities have indicated that they have extra challenges to deal with in attempting to carry out advocacy and in trying to bring about changes through their efforts.

In rural areas there are fewer opportunities for people to develop advocacy skills because most resource people are based in cities and most training occurs in urban areas. Information resources, such as videos, books and kits are unlikely to be available through the local library, community or information centres.

Consumers and carers find it very difficult to get together to work through issues. Some do not even have easy access to telephones. Distance can be a problem and public transport is limited or non-existent. Most people do not have the financial resources to overcome these barriers.

In rural communities, fewer workers are willing to support advocacy as they are reluctant to be seen to be working against services and managers. Questioning authority and dissent are not seen as valuable attributes.

There are fewer options available to people attempting to change things through their advocacy. For example, if consumers or carers are unhappy with a nurse or psychiatrist, they are unable to change the situation because there are no other people practising in those professions in their area.

Consumers and carers are cautious about raising issues connected with services, treatment and attitudes because it is difficult to keep them confidential. Everyone in the community appears to know everyone else’s business.

In general, consumers and carers feel the members of rural communities are less tolerant of people’s differences. This translates into social pressure not to talk about illness or disability and to accept the way services are provided without complaint. Consumers and carers are expected to just accept things the way they are.

Dealing with organisational culture

Large systems, like health services, are very complex to organise and manage. They involve many people, each needing to find his or her place in the organisation as well as to do their work. Every organisation, irrespective of size, has its own culture. Sometimes an organisation’s culture can be identified through what it says or writes about itself. Usually though, the culture tends to surface in the way people who are part of the organisation think, talk and behave. The cultural identity of an organisation is influenced by its purpose, history and experiences. People in the organisation, especially those in positions of power, affect what is seen as important and influence beliefs and values. Over time, people in the organisation adopt the beliefs and values of the organisation and become part of that culture. This can sometimes mean that they think and behave in certain, sometimes predictable ways, in keeping with what is generally expected in the organisation.
Organisational culture can be a ‘good’ thing. It helps create order around complex differences, it provides a strong focus for an organisation’s survival and it creates cooperative strength for an organisation. The people within the organisation are supported through being part of a collective. They are provided with a level of certainty and predictability and are able to operate freely within certain limitations.

Organisational culture also gives people clues about whether they want to be part of a particular organisation or whether their personal values are so different that joining would be intolerable. Whether as a worker or as a voluntary member, people can exercise choice about whether they join, stay in or leave an organisation.

Organisational culture can also be a ‘bad’ thing. Particularly in very large organisations the culture can become somewhat stagnant and resistant to change. Alternatively, sweeping changes, such as those brought about by massive cost-cutting, can cause cultural changes so traumatic that workers within the organisation are left floundering. The subtle assumptions and perceptions associated with organisational cultures can be dangerously limiting to the organisation as a whole and to the individuals within it.

The big challenges for advocacy are around potential culture clashes. It is quite possible that what one person or group wants to present, or how they intend to present it, does not fit well with the culture of the organisation to which they are presenting. The more that is known of the culture of an organisation, the more likely the success in influencing it. Messages can be tailored to fit and be delivered in accordance with achieving the best hearing and response.

Organisations are made up of individuals who bring with them elements of other cultures. These individuals are not just governed by the culture but are part of the influence working on it. Gaining acceptance or agreement from an individual in an organisation may be insufficient if it does not fit well within the larger organisation. It may, however, have introduced a level of influence that begins to shape cultural change. Cultures can and do change, but they do so very slowly. It is worth remembering that today’s advocacy activity can influence the organisation of tomorrow.
Dealing with the bureaucracy

Bureaucracy is a way of organising. Extremely large and highly complex organisations have tended to adopt this approach as a way of managing. It involves a lot of structure and many organisational levels. There are certain rules governing the way things can and cannot be done, there are particular ways of communicating and procedures for communication and there is a hierarchy of workers. Many people say that bureaucracy is not an efficient way to manage an organisation. It has tended to be used by only the largest of organisations and, consequently, government administrations are seen as highly bureaucratic and are accused of being inefficient and ineffective. Bureaucracy may, however, be among the few ways of managing such large structures.

For advocacy effort to have an impact it needs to acknowledge the structure of bureaucracy and address it accordingly. Despite a desire for things to be different, consumers and carers:

- Need to anticipate that response time to approaches will be slow,
- Need to give plenty of notice, say, for a meeting,
- Have to deal with a lower level worker who is unable to make the appropriate decision before they can deal with the right person – you can expect that this is the only way to move your message through the system,
- Have to engage in the process by their rules.

Dealing with the politics

Politics is about power. Most advocacy events have an element of politics about them. This is not the politics of government but rather about who holds or seeks power or control in any given situation. It is useful to know that negotiating the balance of power will occur in any advocacy activity. Either you or somebody else will be seeking to increase their power. Your message may be designed to take more control of a situation or to promote greater sharing of power. Some consumers and carers become concerned about their advocacy activities becoming ‘too political’. The politics of advocacy as a process of redressing the injustices and inequities brought about by power imbalances means that dealing with the politics is inevitable.

At a formal level, politics is also about what governments and government administrations engage in. It is about ensuring that structures are in place that reflect the policies of government which, in a democratic society, attempts to represent the will of the people.

In Australia, political representatives are elected on the basis of what they stand for and the extent to which this is supported by the community through elections. Usually, politicians are identified with a specific political party with its particular policies. Political parties have different policies based on a collective set of beliefs about society. This means that each political party will have different views about social policy. It is within broad social policy that consideration is given to the needs of consumers and carers.
The challenge for advocacy activity is that consumer and carer messages may not be consistent with the prevailing social policy of the political party in power. To the extent that the administration of government is there to put social policy into effect, it should be expected that administrators share the same view as the politicians. This is irrespective of the possibility that they are the same people who supported a similar message before a change of government.

**Dealing with the legislation**

Various laws exist that provide an infrastructure to formal understanding of justice. From a consumer and carer perspective, some laws appear to advantage those with power and disadvantage those without. Legislation is constantly under review. It can be both responsive to social changes and reactive to social unrest.

Laws may be State/Territory specific or have national application. The differences between States/Territories represent a challenge for activity in pursuit of change at a national level.

Some legislation is particularly relevant to mental health interests. The various States/Territories maintain their own mental health acts that continue to go through amendments towards a more consistent national outcome.

Some legislation has been represented as enabling for people with disabilities or proactive in ensuring no disadvantage in a general sense. *The Disability Discrimination Act* is an example of the former and equal opportunity legislation an example of the latter.

Addressing legislation through advocacy is particularly complex. It is a political process requiring negotiation of substantial hoops and hurdles to bring about change. It is also a conservative process. Existing laws need to be demonstrated to be inappropriate before change is considered.

Advocacy may be directed to legislative change through organised political activity. Alternatively, it may be directed towards issues of rights infringement, inequity and injustice that current legislation may be seen to perpetuate.

**References**

Hutchinson M and Ausland T *User Participation in the Mental Health System*, Mind, London, pp13-20,


*Disability Services Act 1992 (Commonwealth)*
Maintaining personal effort in advocacy

People undertake advocacy as an individual or as a member of a group. Generally people who carry out advocacy do so in both forms at various times depending on the situation. There may be times when you feel particularly concerned with an event or circumstance and you may decide to have your say and become involved. Individual advocacy can relate to your own issues (individual self advocacy), or can be on behalf of someone else (individual peer advocacy). This section is about maintaining personal effort in relation to individual advocacy.

Much of the work carried out by individual advocates is unpaid. However, there are a growing number of people who receive payment for their advocacy work. One of the most visible forms of paid individual advocacy in mental health is consumer consultants. Most States in Australia now have consumers who undertake a range of work, either as paid consumer consultants, or as independent consumer consultants. Below are some examples of work that can be carried out by a paid consumer consultant:

- Acting as an advocate for clients of the mental health service,
- Informing people of their rights and responsibilities in mental health and other services,
- Finding options to resolve a problem,
- Locating appropriate services,
- Lobbying on proactive and reactive issues,
- Investigating grievances,
- Acting as a support for consumers attending various tribunals and hearings,
- Attending meetings of various government agencies in relation to mental health,
- Reading documents relating to current developments, locally and nationally,
- Carrying out administrative duties as required by the employer,
- Enabling others to become successful self advocates (empowerment),
- Providing consumer-focused training to service providers.

Putting yourself forward

The first step is to decide whether you really want to undertake advocacy activities. There may be many different motivating factors which lead people into becoming advocates and it is a good idea to examine your own reasons for becoming involved. Talk to people who are working as consumer advocates and see what’s involved, both positive and negative. Once you have decided that you want to do advocacy work, you can begin.
Advocacy can be conducted formally and/or informally and in relation to a number of broad issues. To be an advocate in the formal sense, you need to notify various agencies and groups that you are available. You may have specialised skills in certain areas, for example, you may have a lot of experience in sorting out housing disputes. This may be the only specific area of advocacy that you want to be involved in. You can gradually learn about other areas of advocacy that you may want to get involved with in the future. Remember to always look after yourself and don’t overextend yourself.

To be an advocate in an informal sense, you may respond to various issues brought to public attention via the newspaper, radio or television. You may write a letter to the editor of the newspaper advocating for a particular stand or viewpoint, or you may ring up the talkback radio program to put your view across. Situations may also arise where you have the opportunity to attend community consultations, public forums, focus groups and other meetings. These are all situations where you can informally advocate for the empowerment of consumers of mental health services and their carers.

Taking care of yourself

Being an advocate can be a demanding role. When people first become involved as advocates it can be exciting and fulfilling: ‘There’s so much that needs to be done; let’s get into it’. However, very quickly this can become overwhelming: ‘There’s too much to be done and there are many forces against me. How am I going to maintain my energy?’ Perhaps the most important thing to learn is how to take care of yourself so that you don’t burn out. There are some fundamentals in taking care of yourself that are essential to any person undertaking stressful work – and advocacy can be stressful:

- Maintain links with friends/family not involved in advocacy issues,
- Eat well – ensure that your diet is nutritious and that you eat even when you do not feel like eating – stress can reduce appetite,
- Ensure that you obtain sufficient rest and sleep,
- Ensure that you exercise – for example, going for walks and swimming can be mentally and physically very beneficial,
- Take up a hobby and pursue it regularly,
- Obtain emotional support from individuals that you respect and trust,
- Take time out occasionally – be self-indulgent,
- Understand that, despite all your advocacy work, there will always be issues to deal with and that you are not responsible for resolving all these issues – understand your own limits. (Also see 1.1: Looking after yourself in Skills, Strategies and Tools.)
Choosing an advocate for yourself

At some time you may want an advocate to act on your behalf. It may be useful to have a prior arrangement with a person, or persons, to act as your advocate when you do not wish to represent yourself for a number of reasons (for example, you don’t have specific understanding of the particular issue; the issue may involve a large powerful organisation; the issue may involve a person who has a clinical relationship with you). By making an arrangement in advance you have time to choose an advocate that can best represent you. The ideal qualities, knowledge and skills of such a person are:

- A person who has first-hand understanding of the problems you are facing; that is, the person has empathy,
- A person who has good communication skills,
- A person with knowledge and understanding of the decision-making processes of the advocacy target agencies – choose an advocate with particular expertise in the area that you require advocacy,
- A person who can harness resources to assist in advocacy,
- A person who can assist you to be more able to conduct advocacy on your own behalf and for others in the future,
- A person who is strongly committed to advocacy and doesn’t give up easily,
- A person with a good reputation on human rights and justice,
- A person who will be loyal to you over time,
- A person with passion, who really wants to make a difference.

If you have chosen an advocate but are unhappy with the way things are going, talk to your advocate about your concerns. If you are not sure of the advice you are getting, always get a second opinion. Be open and honest with your advocate in doing this; a good advocate will have no problems with you seeking a second opinion. (Also see 1.9: Creating a personal advocacy plan in Skills, Strategies and Tools.)

Being an advocate for a peer

Being a peer advocate can be an extremely rewarding and empowering experience. Because of first-hand acquaintance with mental illness and the mental health system, consumers and carers often possess unique insights and practical skills for operating within the system. Peer advocacy works very well because of its focus on people with first-hand experience assisting others going through similar experiences. Peer advocacy also focuses on empowerment by enabling peers to take up the advocacy challenge themselves and enjoy the rewards of self advocacy.

What do you do if asked by another consumer or carer to advocate on their behalf? First, think carefully about your relationship with this person. Be wary if you are considering advocating for someone who is a close friend, as it can be easy to lose objectivity – sometimes you can be too close. You may be involved in the advocacy issue itself and cannot see the whole picture. If you feel that you are too close to this person to effectively advocate, try to locate another consumer or carer to advocate.
To be an advocate for a peer, consumers and carers have the ability to empathise with people who are going through similar experiences as themselves. This is really what distinguishes ‘peer’ advocacy from other forms of advocacy. It is this shared experience which bonds people in a relationship of sensitivity and genuineness and is the strength of peer advocacy over other forms. Peer advocates also need to have passion and energy for the issues facing consumers and carers.

Peer advocates have to be able to put their own problems to one side and not let them negatively affect their advocacy work. In other words, the motivation to advocate for a peer is not to redress the injustices which occurred in the past, but to tend to the needs of the person receiving advocacy.

An important question to ask yourself before agreeing to be an advocate for a peer is: ‘Do I have the personal support systems in place so that I can maintain my effectiveness as an advocate?’ If the answer to this is ‘no’, then a support system needs to be developed before agreeing to be an advocate.

Other issues which need to be considered are the availability of time and resources. Being a peer advocate means that you need to be available to the person you are advocating for. The exact amount of time and the periods you are available need to be negotiated. Accessibility is essential. Personal resources such as a telephone and a means of transport are also important.

**Attitudinal change in advocacy**

A major part of advocacy is to do with attitudes: either changing people’s current attitudes, or influencing the development of a particular attitude. Consumers and carers involved in advocacy promote positive attitudes towards mental illness and people living with mental illness, and attempt to change negative attitudes in these areas. For the person undertaking advocacy, perhaps the most important aspect about attitudes is to recognise that, as they are learned, they generally can be changed.

People usually hold and express attitudes because they receive some sort of benefit from doing so. A person may adopt a positive attitude towards someone or something because it helps in achieving a desired goal or meeting a specific need. For example, a person may adopt a positive attitude towards rainforest conservation because of the feeling that he/she needs to do more to preserve the environment. Attitudes may be formed as protection against acknowledging basic truths or confronting the harsh realities of the world.

Some people derive satisfaction from expressing attitudes appropriate to their personal values and to their self-concept. For example, a psychiatrist may have a domineering attitude because he or she believes that doctors are important people who deserve respect from others. A function of attitudes can be that they organise people’s perceptions and beliefs about the world. This is sometimes called a ‘world view’ and is the way people ‘make sense of the world’.
Attitudes are generally, but not always, related to behaviour. Usually, if people have a positive attitude towards something then they behave positively towards the ‘something’, and vice versa. However, this is not always the case. A manager of an organisation may have a positive attitude towards people living with a mental illness, but when it comes to employing them, a lot of reasons come up why this can’t be done. Conversely, a car salesman may have a negative attitude towards ‘foreign’ people, but when one comes into the yard to buy a car, his behaviour suggests that he really likes ‘foreign’ people.

The strength of the relationship between attitudes and behaviour depends on many things. People are very different from each other and hence show stronger or weaker attitude-behaviour relationships. When things that are considered socially appropriate are favourable to certain attitudes, behaviour is more likely to reflect these attitudes. Having something to gain from an attitudinal issue (such as the car salesman above) also strengthens the attitude-behaviour relationship.

**Influencing behaviour**

If in your advocacy efforts you wish to influence someone’s behaviour, what can you do? You can try to persuade people to adopt a certain attitude. For example, you can try to persuade an editor of a newspaper that articles about mental illness need to be based on fact. This is using persuasive communication.

Persuasive communication

Persuasive communication is probably the most widely used strategy for influencing attitudes in today’s society. Advertisements on television try to persuade viewers that a certain product is the best and that they should get it; politicians try to persuade the people that they are doing a great job at running the country and should get their votes.

There are three essential elements and a common structure to persuasive communication: a communicator sends a message to an audience. There can be a number of factors that facilitate the acceptance of the message by the audience so that their attitudes, and therefore their behaviour, are affected. An attitude change can occur when a persuasive message is understood by an audience after careful thought. The message is examined from various perspectives and accepted as reasonable. For example, the Governor-General may present an argument calling for more positive attitudes towards mental illness. The people in his audience think about his argument, understand what he is saying, and decide that they will adopt a more positive attitude.

Attitude change can also take place when a persuasive message is only partially understood, that is, the message is accepted without much thought. For example, a person may adopt positive attitudes towards mental illness because the Governor-General, who is a person they admire and respect, argues for the community to adopt more positive attitudes. The people in the audience don’t fully understand what he is saying, but on the basis of their respect for him, they are prepared to go along with what he is saying.
People generally think about a message if they have the ability and the motivation to do so. The important thing is to get them to think about the message. If their thoughts are generally in favour of the message, their attitudes are likely to be in favour of it. If their thoughts are generally against the message then their attitudes are likely to be against it. While you can’t really influence the ability of people, you can influence their motivation. People are likely to be well motivated to process messages if the issues are about topics which are of personal relevance to them and have significant consequences for their own lives.

If you wish to produce an enduring change in attitudes and to alter behaviour as well (a major aim of mental health advocacy), try to have the audience process the message deeply. In other words, try a strategy that ensures the audience has to think very carefully about the message. Attempt to convince the audience that your argument is the best alternative by providing strong and defensible arguments. Involving the audience in role-plays to promote deep thinking is an effective attitude-change strategy.

**Minority influence of the majority**

Although facing daunting odds, minority groups can and have influenced the majority of society. In fact, many studies have shown that members of minority groups, or majority groups, can exert influence and be influenced. Where behaviour and argument by minority groups are **consistent**, changes in the majority’s attitudes and behaviour occurs. A consistent minority is generally perceived as being confident and is seen to have certainty and competence, which leads to an appreciation of their message.

One way of trying to influence a majority (for example, consumers and carers trying to influence the health care system), is to start a conflict with the majority by not conforming from the beginning and by consistently challenging the majority’s position. Over time, consistency and commitment by the minority to the alternative point of view marks their argument as more and more acceptable. For example, consumers and carers may refuse to accept or support service standards developed solely by a mental health service and consistently challenge the legitimacy of the standards. Consumers and carers may become committed to this stance and involve others to take a similar position. (Also see 5.7: Developing a campaign in *Skills, Strategies and Tools*.)

Another way is to have initial conformity to the majority position, which enables the minority group to gain acceptance and demonstrate competence in helping the majority group work toward its goals. Once the group has gained acceptance and is looked upon favourably, it can use its acceptance and status to oppose the majority view, to offer alternative views and to put forward the goals and policies that are important to them. This can be thought of as ‘changing the system from within’.

Both of these strategies can be effective given the appropriate circumstances. The first strategy, however, is a confrontational approach which can lead to individuals from minority groups being singled out as ‘stirrers and aggressive types who aren’t willing to negotiate and be flexible’. However, the situation may be so unacceptable that this approach is warranted.
The second strategy is a slower approach and is more likely to be successful where the minority group has gained widespread acceptance from the majority, especially a powerful majority. An individual who is trying to maintain his/her efforts in influencing the majority has to consider the costs of confrontation, including how long a period of time the confrontational approach can be maintained. However, this may be appropriate for large or powerful majority groups that will only change their views and attitudes over a long period of time. Trying to change such groups with an immediate confrontational approach may lead to burn-out and feelings of despair for minority group members.

Deciding which approach to use is ultimately up to individuals after weighing up the whole situation. Whether an individual belongs to a group or is acting as an independent advocate is one of the factors to be taken into consideration. In regard to maintaining personal effort, the question for consumers and carers is: ‘Can I maintain the approach I am considering in a consistent way with enduring commitment?’.

**Powerlessness at the individual level**

One of the greatest obstacles to maintaining your personal effort in advocacy is feelings, and realisations, of powerlessness. Historically, people living with mental illness have never been allowed to exercise the level of power that is enjoyed by the general community. In fact, they have been actively disempowered to the point where many have felt that they don’t really have much to offer the community and have no right to challenge others. In the last few decades this has been changing. People living with mental illness have much to offer, but the process of disempowerment has been so pervasive for so long, it is not easy for them to suddenly pick up that power that is offered and to ‘become empowered’.

Many consumers are suspicious of these offers of power, and with good reason. Often consumers are offered power in one situation and then totally disempowered in other situations. For example, a manager of a mental health service may invite consumers to join a management committee which manages the operation of the service, and may be very sincere about their involvement. However, the very same consumers may get a totally different reception from the staff at the inpatient ward at the hospital of the very same service.

Another factor in all of this is the issue of ‘tokenism’. This happens when consumers and carers are asked for their involvement and, on the surface, it appears that the authorities are willing to hand over power to them – but it’s all for show. For those willing to be involved this can have a demoralising effect. Consumers often initially feel great enthusiasm, believing that the offers of power-sharing are genuine. When they find that this is not always the case – perhaps is hardly ever the case – they stop their involvement.

The amount of power possessed by those who run health services, make and uphold laws, provide information via the media and so on is immense. It is daunting for any individual or group to take on authorities of power, let alone a group of people who have been systematically disempowered over centuries.
A major role of consumer and carer advocates is to change this situation. Preparation for life as a consumer or carer advocate is the first step in maintaining personal effort in advocacy. Understanding that you are going to feel demoralised, treated tokenistically and hurt is the first step in this preparation. Having knowledge, skills and support is the best way to maintain effort. These resources are designed to provide some of the knowledge and skills, with some suggestions on how to obtain support.

Some ideas for reducing feelings of powerlessness and assisting in the maintainence of personal effort in advocacy include the following.

Finding a mentor
No matter how much experience you have with mental illness, mental health services and/or advocacy, you can always find others people with different experiences from whom you can gain increased knowledge and support. They are not ‘gurus’ but mentors from whom you can draw guidance in the work you are undertaking, as well as a means of direct support for the times when you feel overwhelmed, ineffective and ready to give up.

Peer support
Conducting advocacy is demanding and stressful. Besides having a mentor, obtain support from other consumers or carers undertaking similar work. This is very important for individual advocates working outside of a group. It is very easy to lose perspective and to feel isolated when working alone.

Obtain debriefing
Consumer and carer advocates also need opportunities for debriefing from situations which can affect them in a very personal way. Advocates deal with many sad and distressing issues, some of which they have personally experienced in the past. It is essential that these issues are talked through with others who are trusted and respected. A mentor can be one source of debriefing; peers can be another. Advocates need to ensure that they don’t become unwell themselves, as they are of no assistance to anyone if this occurs.

Devote time to self-care
Develop strategies to identify, monitor and reduce the stress that occurs as a result of advocacy activities. Groups can organise stress relieving workshops on a regular basis for members, and perhaps accept individual advocates into these courses. Individual advocates must ensure that they have ways of reducing stress that work for them. Strategies can also be developed to monitor the effectiveness of advocacy activities. By observing successes, individuals can feel good about their work and be further motivated to continue. (Also see 1.1: Looking after yourself in Skills, Strategies and Tools.)
Obtain appropriate learning experiences

There is never a point where any person can say that he or she has all the knowledge and skills needed. Ongoing education and learning experiences are essential for people engaging in advocacy and community development.

There are a number of skills which are useful in maintaining a personal effort in advocacy, community development, and across a range of situations. Many of these are included in this Kit and can be used to complement the knowledge gained from this section.

References

Engaging networks and organisations

Throughout this section, the words ‘group’ and ‘organisation’ are used interchangeably.

Organisations, networks and links

Many people like to carry out advocacy activities as part of a group and there can be a number of positive reasons for joining or starting a group. Group advocacy is conducted by individuals who get together to represent, challenge or campaign on issues which affect other individuals or groups of people. Beside the actual advocacy issues that the group is involved in, particular attention must be paid to the development of the group. To be effective in whatever activity an organisation is set up to do, it must be developed along sound group development principles to ensure that the structure is strong and will last into the future.

Once an organisation is established, it is important that networks and/or links are set up with other organisations involved in similar activities. This can be done by contacting similar groups and mental health organisations to discuss your ideas. All organisations may not be interested in linking with the group but, through networking, contacts can be formed that can provide names of other groups and organisations that may be interested. Follow this process through and meet with representatives of these organisations to discuss the group’s plans and possible links with existing groups.

Decisions need to be made as to the extent of these links, taking into consideration various issues. For example, consumer and carer organisations can often experience problems when they join with existing organisations. The existing group may view the relationship as a licence to interfere and demand a role in policy development, committee selection or other activities. This is particularly the case if the existing organisation takes on the role of sponsoring or ‘auspicing’ the new group, that is, taking financial responsibility for the group. Through this, the group’s independence can be lost. However, independence itself can be dangerous, as the new group can become isolated and not exposed to all the knowledge that is required for an organisation to be successful. (Also see 5.3: Gaining support and fundraising in Skills, Strategies and Tools.)

Rather than linking with an existing organisation, a new group may consider networking with other groups. This may be through a newsletter, regular meetings, telephone hook-ups and, more commonly today, through the Internet. Networking keeps groups in touch with current activities, stories of success or failure and hard-won knowledge that other groups have acquired. Networking gives many of the advantages of linking up with an existing organisation, except that the group takes full control of all aspects of its development and activities.
Developing peer advocacy groups/organisations

Peer advocacy groups are specifically those groups whose members conduct advocacy only on behalf of their peers. A mental health consumer peer advocacy group is where consumers advocate on behalf of other consumers. A mental health carer peer advocacy group is where carers only advocate on behalf of other carers. Many people report that they only want people who are in the same situation as themselves, or have been through the same experiences, acting on their behalf as an advocate. A consumer peer advocacy group may take up general issues which affect their members such as stigma, discrimination, accommodation and rights. Peer advocacy groups work on the basis of mutual support, common interests and issues. (Also see 4.2: Starting up a group and 4.3: Developing your group in Skills, Strategies and Tools.)

How organisations thrive

Organisations that thrive are those that devote time and energy to ensuring that the organisation has a sound structure and an understanding of group dynamics and processes. Individuals who come together, start a group and immediately start working on the issues, invariably face an organisational crisis from which they cannot recover. This is not particular to consumer groups or advocacy groups; all groups, whether sporting, business or political, need to focus closely on organisational processes.

Organisations that thrive are those that are prepared, have an understanding of the pitfalls that are lying around the corner and have plans to deal with them. Consumers and carers often don’t want too much structure; they are sick of rhetoric and meetings and seeing nothing improve and they want to quickly get into the issues. While this is understandable, it’s a recipe for organisational collapse. Successful organisations devote all of their formation period to establishing structure and leave the issues to the side until they have the strength and capacity to deal with them.

Organisations that thrive are also characterised by an appropriate management structure. A major reason for group failure is an inappropriate leader. An appropriate leader is one who is skilled in group development; understands the issues the group will pursue; is motivated; can motivate others and, most importantly, can empower others in the group. There is a danger when there is a leader who is so good at ‘leading’, but cannot assist others to become empowered, that she or he will take on the entire management and direction of the group, leaving other members feeling left out, not needed and disempowered yet again.

Even when group members are happy to leave everything up to the leader, a major danger lurks. If the sole leader/motivator of the group ‘burns out’, leaves town, becomes ill or just leaves the group, other members are unprepared to take up the role of the leader and the group is in organisational crisis. (Also see 4.4: Leadership in Skills, Strategies and Tools.)

Organisations that thrive can also be characterised as those that adopt a proactive stance (that is, putting forward ideas) rather than only reacting. Advocacy is often seen as simply about reacting to something perceived to be wrong. Advocacy can also be about putting forward a viewpoint which others may not have considered, that is, being proactive. Organisations need to be flexible, know when to be reactive and when to be proactive. Above all, to be successful, organisations need to focus on achieving outcomes in a manner that reflects the shared purpose and direction of all group members.
Gaining financial and other support

All groups and organisations need financial and non-financial support to survive and grow. Reliance on group members to purchase the equipment needed by the group is a short-term measure that, if ongoing, will guarantee the failure of the group. Costs quickly add up. There are phone calls to make; people to be picked up and dropped off; refreshments to be purchased for meetings; stationery to buy and more. This can easily add up to two or three thousand dollars a year; a lot of money for individuals to spare. Finding support is perhaps one of the hardest tasks the group has to undertake. One way of finding support is to convince various community and government agencies that what the group is doing is valuable and necessary to the community. There are a number of service clubs, such as Apex and Rotary, whose role is to raise money and distribute the funds to worthwhile community groups. This is generally one-off funding for specific purposes.

Another way to obtain financial support is to formally apply for funding from government departments that distribute community funding grants. This requires the writing of detailed funding submissions, a complex process. However, networking with other groups that have already done this can be of great assistance. Groups that are not incorporated, or are not auspiced by an incorporated organisation, cannot be granted funding by most funding bodies. As discussed above, groups can link with other groups in order to obtain ‘sponsorship’ to ensure some measure of financial security. This is generally done by approaching an incorporated organisation to auspice the group. (Also see 5.3: Gaining support and fundraising in Skills, Strategies and Tools.)

What is auspicing?

When individuals get together and form a group that relies on funding from another organisation, one of the first difficulties they face is to work out how the group is going to actually receive the money being granted to them. Does the group open a bank account? If so, the bank requires a lot of details about the group and the people who will access the account. Then there are the difficulties of working out which people from the group will manage the money. Funding organisations require detailed accounts to be kept of where and how the money is spent. Financial statements need to be supplied to the funding body on a regular basis. The group that receives the funding is accountable for the money to the funding organisation and this can place a lot of stress on the people in the group who are responsible for its management, as well as consuming a lot of their time and energy.

A way to get around these problems is to arrange for an organisation that is incorporated, and has an accounting system which is audited annually, to auspice your group. For a small fee (generally a small percentage of the funding obtained, for example, five percent), such an organisation will bank the money your group receives, monitor its spending and prepare monthly financial reports for the group and for the funding organisation. In this way the auspicer takes responsibility for taking care of the funds, and for ensuring that it is spent for the purposes that it was given by the funding organisation. Your group still has control over how the money is spent, so long as it is spent in accordance with the budget that the group submitted to the funding organisation.
How to find an auspicer?

Any organisation that is incorporated can be an auspicer. In your local area examples are community centres, neighbourhood centres, church organisations, mental health non-government organisations like State Associations for Mental Health; consumer organisations, Schizophrenia Fellowships, GROW, ARAFMI, Richmond Fellowships and other non-government organisations not connected with mental health, such as advocacy centres and community resources units.

What about becoming an incorporated organisation?

Incorporation is a legal act controlled by government processes. It is similar to establishing a company to run a business. Incorporation is not recommended to groups that have recently been formed, but rather is something for groups/organisations that have survived the early stages of group development and have achieved relative stability. There is generally a fair amount of organisational upheaval during the process of incorporating, which is best faced by an group that has achieved stability and has a sound structure. (Also see 4.10: Becoming an incorporated body in Skills, Strategies and Tools.)

Groups and organisations also need non-financial support to be successful. It is often easier to obtain equipment and services rather than money. Office equipment such as furniture, computers and printers may be obtained second hand from various sources. Some organisations may be able to offer office space and secretarial assistance. Volunteers can also provide secretarial support. Lobby various people and organisations through personal meetings, telephone calls and by letter to obtain such support. Moral support is also very important; it’s very easy to feel isolated. Communication with other groups and organisations can provide this support.

Problems associated with external funding

Once a group starts receiving funding a potential problem of ‘conflict of interest’ can arise if certain demands conflict with the values of self-help and consumer empowerment. Groups that don’t address these issues run the risk of losing touch with their guiding principles and their reason for existence. It is very easy to allow pressures from outside to mould the group into something it was determined it would never become when it was first formed. Sometimes groups find themselves resembling the very same organisations they are lobbying against. It takes a willingness to experiment with a different way of doing things, and constant vigilance, to ensure the group is not slipping into ‘bad’ habits and to keep it on track with its original aims and principles.

Consumer/survivor Joyce Kasinsky from the United States provides the following advice for groups to protect themselves from what she refers to as ‘provideritis’ following the acceptance of government funding:

‘It is possible for self-help groups to successfully utilise government and mental health system funding despite the fact that strings are attached. These strings can be sizeable; a self-help group may be put into the position of collecting data, keeping all sorts of records and performing evaluations under the government’s close scrutiny.'
Be firm about what you will do and what you refuse to do right at the beginning – and stick to it. Many groups have written into the funding proposal itself the kinds of things that they would and would not do, as well as their goals and philosophy. For example, if your goal is to reach the widest possible group of ex-patients, made up of people who won’t use “government and traditional mental health services or any program that might limit people’s freedom or treat them in a dehumanising way,” you will have to make your needs for confidentiality and freedom from oppression and control perfectly clear to the government funding agency. You must stand your ground and state exactly how your group intends to collect statistical evaluation data, what records will and, most importantly, will not be kept, and other issues about access to these records.’ (Joyce Kasinsky in *Reaching Across, p178*)

If the group has a mechanism for monitoring its activities and performances (also see 4.3: Developing your group in *Skills, Strategies and Tools*), you are likely to see the warning signs that the group is beginning to conform to the wishes of the funding agency.

**For example, the agency that provides funding to the group begins to assert control in day-to-day operations and decision-making.**

If the group has negotiated the role of the funding agency, and it is clearly stated in the funding agreement that the funding agency cannot assert such control, this needs to be pointed out to the funding agency. If this is not written into the funding agreement then it is more of a problem. Negotiations will need to take place between the group and the funding agency. (Also see 1.6: Interpersonal communication in *Skills, Strategies and Tools.*)

While groups should never ‘do the bidding’ of their funding agency, it is important to maintain a positive relationship with them. Some tips for doing this are:

- Work in partnership with the funding agency in regard to the overall aims of the group and how the funding generally will be used – this can be done without compromising the goals and principles of the group,
- Listen to their advice and opinions – you don’t have to follow them,
- Utilise their technical and process knowledge and skills – but apply these to suit the group’s goals and principals,
- Communicate the successes of the group to the funding agency so that it understands that the money is being well used.
Communication between organisations

As a group, never try to ‘go it alone’. There are too few resources available for groups to be ‘reinventing the wheel’ and not learning from the mistakes of others. It is essential that groups establish links with other organisations. It is difficult for a group to successfully advocate for change in isolation. Consumer and carer groups that achieve successful advocacy often work in coalition with groups that are natural allies in the health, disability, housing and legal fields. Isolation and breakdown in inter-group communication result in the loss of power and can be one of the biggest threats to the success of a group.

Work with, not for, other interest groups. Contribute articles to their newsletters, send representatives to their meetings and events and encourage them to reciprocate. Explore common purposes and how resources can be shared to ensure maximum productivity. Work with others that accept the group’s members as equals. Working in coalition does not mean group members must agree with other group members on all issues; it means harnessing and sharing limited resources.

The most cost-effective manner of communication to the greatest audience is through the development and distribution of a newsletter. This requires some financial resources to set up, such as the purchase of a computer and printer. There are also ongoing expenses of stationery and stamps to meet. Another strategy is to put the group on mailing lists of all organisations and agencies that are relevant to its work. It can be useful to have a spokesperson for the group; this can be the leader or someone else with specific skills and resources to take on the position. (Also see 5.4: Developing a newsletter and 2.9: Managing a contact list in Skills, Strategies and Tools.)
Collaboration between groups

To maximise effectiveness, in terms of both finances and outcomes, many groups collaborate with other groups in a general way, or on specific projects. In some places these are called alliances. An alliance may form as a contingency plan for situations where various groups want to present a united front on matters affecting all consumers and carers. For example, a local mental health service may announce that the Mobile Intensive Treatment Team is being disbanded. If there is an alliance of mental health groups already in place it can immediately swing into action, conducting media and community campaigns. If not, individual groups have to utilise their own limited resources to undertake the same work.

Alliances can also be useful in conducting proactive advocacy and community development programs. For example, Mental Health Week is an event in which many mental health groups participate. Rather than each group doing only their own thing, it makes sense to pool resources and conduct some combined events. Groups need to be aware of the activities and processes of other groups. Inter-group meetings can be held regularly so that the groups get to know each other and gain an understanding of each other’s needs and resources. Progress on a joint project can be appraised by representatives from each group and this information relayed back to the members of the various groups.

Peak bodies

Like alliances, peak bodies are organisations formed to represent the views of a number of smaller groups and organisations. Some alliances may actually become a peak body, but this does not necessarily have to be the case. Many small community organisations fight very fiercely to retain their independence and refuse to acknowledge that a peak body represents their views.

Peak bodies are generally formed to enable groups and organisations to have their views represented at State/Territory, national and international levels, and to provide policy makers and government with a single body to communicate with. There are literally hundreds of mental health groups and organisations throughout Australia, and it is quite impossible for all of these to have access to government and policy makers at the State/Territory and national levels.

An issue which peak bodies need to continually address is that of representativeness. It is difficult for peak bodies with only a relatively small number of members to represent and reflect the opinions of those they claim to represent. Many groups become disillusioned with peak bodies and do their own lobbying. With the tremendous advances in communication technology, such as the Internet and video conferencing, the need for peak bodies is often considered to be less important than it once was.
Advocacy groups and legal issues

The work of an advocacy group can be extremely varied. At times the group can come across situations requiring specialist skills and knowledge. Perhaps the most common of these concerns legal matters. Consumers and carers can be involved in legal issues across a number of situations, such as involuntary regulation; patient review hearings; discrimination issues; issues relating to the Mental Health Acts; power of attorney and situations which bring some people living with a mental illness to the attention of the police. Legal advocacy is being represented in court by a lawyer (a solicitor or a barrister). Examples of legal advocacy include appealing through the legal system against detention in hospital; being represented in a hearing by a magistrate in a compensation claim, law suit or trial.

Because legal advocacy works within the legal framework and structure, peer advocacy groups generally do not have the specialised skills required for such activities. There are generally a number of legal advocacy organisations operating in the larger cities that offer services to the community. There are also generic advocacy organisations that can offer some more basic assistance and act as a referral agency to more appropriate assistance. Mental health organisations, such as the various State Associations for Mental Health, can also be very useful in locating appropriate assistance. It is important, however, for the advocacy group to retain control over the overall process and not to allow the legal advocates to contravene the group’s processes or its mission statement.

This applies equally to other specialised help the group may require. Use the services offered by these organisations as various tools in a tool kit are used. The group needs to learn which tools are most useful in a given situation, and it is the ability to do this well that denotes successful advocacy groups. Find out what specialised advocacy services are available in the community and make contact with them so that the group fully understands what support there is. Ask to be put on their mailing lists.

Mobilising family and social networks

An area of networking often overlooked has to do with sections of the community other than similar groups and organisations. For example, family networking attempts to bring together the many members of the family and friendship social network. This type of networking can be particularly useful for individuals conducting advocacy activities who don’t have the support structure of a group. The aim of family networking, known by some as ‘re-tribalisation’, is to:

- Facilitate open communication and sharing of information,
- Bring about a renewed sense of cohesiveness and hope,
- Identify specific resources in the network which may assist in solving the problem.
The Internet

Another way to network with groups and individuals is via the Internet (the ‘Net’) or the World Wide Web. Not long ago this technology was only available to a small number of people; often only those who could afford the costs. Increasingly the ‘Net’ is becoming more accessible, especially to groups and organisations. Individuals can also access the ‘Net’ at the local library and, often, at community centres. There is a large amount of material on the ‘Net’ and the benefits are that the material is up-to-date and world-wide. (Also see 2.4: Finding relevant information in Skills, Strategies and Tools.)

Working with mental health professionals

Mental health professionals can be good resources for individuals and groups engaged in advocacy. Although a professional can also be a consumer and/or a carer and a member of the group, or entitled to membership of the group, this section refers to professionals who aren’t members of the group.

The important thing to remember, as it is when involving all professionals, is to use the professional only as an additional resource on a time-limited basis. In a self advocacy group, professionals need only attend group meetings on an invitation-only basis and not become members. In conducting advocacy and community development there is information that you need to have, such as the decision-making processes of organisations that may be the target of advocacy efforts. Professionals can provide this information by being invited to speak at group meetings, and by referring the group to others who have information relevant to the group’s needs.

References

Zinman S, et al (Eds) as cited in Yaskin (Ed), 1992
The mental health system

Introduction

Advocacy activities directed at mental health services need to be based on knowledge of the mental health system at the local, State and national levels. To be able to make informed decisions when working with ‘the system’, knowledge is required of the recent developments in mental health service provision, the structures of mental health services within Australia and current national standards for mental health services.

Obviously this is a big topic, where hundreds of pages can be written without covering everything. As there is no scope here to do that, only what is considered vital for consumers and carers conducting advocacy is covered. Inevitably material will still be missing, although the references provided at the end of this section can assist readers to find more information.

Warning

A word on jargon

Throughout this section you will come across a number of words and terms which may appear to be ‘jargon’ and, in fact, may be jargon. In conducting advocacy and community development with organisations and agencies (such as the mental health system), knowledge of what this jargon relates to is needed. For example, ‘the medical model’ may be considered jargon by some, but to work in advocacy within the mental health system, it is essential to know that there is such a thing as a ‘medical model’. You don’t have to speak the ‘lingo’, and you can actively discourage it but, to be effective, you do have to understand what it means.

Another point is that what is jargon to one person is not necessarily jargon to another. To a person who is into computers, the ‘Net’ or the ‘Web’ are just terms, but to others not so interested they may be jargonistic and annoying.

Any jargon used here is done so in context, and covers the words and terms which crop up frequently in the work of a mental health advocate.
Recent developments

One of the greatest developments in the provision of services for people diagnosed with a ‘mental illness’ has been the change to thinking in terms of ‘mental health’ (a positive) rather than mental illness (a negative). This has led to a focus on mental health and, since the 1940s, there has been a tremendous increase in public awareness and involvement in mental health issues. With this public awareness has come many complaints about the treatment of mentally ill people.

Before the 1950s, as a result of the moral reform, social controls and the various laws in place, there were large numbers of people living with mental illness in institutions, in prisons as well as in the community. They were mainly looked after by unqualified and unsuitable people as staff were provided with little training. Once admitted to institutions, people were usually not discharged. Many of the discharges were actually deaths. The fact that there were no facilities within the community for people who needed long-term care led to the long-term institutionalisation of people diagnosed with mental illness.

Since the 1950s there has been a strong push for deinstitutionalisation, or the movement of large numbers of patients from psychiatric institutions back into the community. It had become obvious that the psychiatric system was failing to effectively treat people diagnosed with mental illness. Because the system was designed to concentrate on acute (immediate) symptoms, it failed to deal with the problems created by the illness, and was unable to deliver treatment in an efficient and equitable manner. It was quite apparent that institutions were being used as places of confinement, a place to keep the ‘mad’ people so that they didn’t bother the ‘normal’ people going about their daily lives.
There were, and still are, many critics of deinstitutionalisation. While the concept is generally accepted, the process has received widespread criticism. Planning has been short-sighted and inadequate and, in many cases, the system of care has simply been moved from the hospital to the community. It is generally accepted that it is financially less costly for governments to provide appropriate services to people in the community than in hospitals. As the number of patients in the hospitals decreased, funds were expected to transfer to the community but, on the whole, this has not occurred.

Nevertheless, research evidence supports the value of good community treatment. The closure of beds in large psychiatric hospitals has been replaced with an increase in beds in small units within general hospitals. Emphasis has been placed on keeping people out of hospital as much as possible, with mobile and extended hours services designed to assist people in the community rather than in a hospital environment.

**Structure of mental health services in Australia today**

The provision of mental health services in Australia is a complicated business, due largely to Australia having six States and two Territories. Each of these have their own governments and their own way of doing things. States and Territories obtain their overall funding through State taxes, but also from the Commonwealth government. State and Territory governments are responsible for the delivery of specialised mental health services with funding from several sources:

- State and Territory governments,
- Commonwealth government,
- Private health insurance funds,
- The community (including co-payment by consumers).

To ensure that funding obtained by State and Territory governments goes into the provision of mental health services, these governments and the Commonwealth have made a commitment to protect (or ‘quarantine’) this funding. This is done through the Medicare Agreement which provides funding for health, based on certain conditions that the States and Territories agree to follow. In broad terms, the Medicare Agreement requires governments to:

- Maintain the current level of expenditure on specialised mental health services,
- Reinvest any resources released from closure or rationalisation of mental health services back into the mental health program.

These are broad principles and there are differences between the various Commonwealth-State/Territory agreements in what is meant by the principle of ‘maintaining mental health expenditure’.
Who funds what?

It can be very difficult to work out and then remember who has responsibility for funding various programs. A concept that some people find easy to remember is that the **Commonwealth** has a responsibility to fund programs that have a national significance, such as community awareness and education, or the development of the National Mental Health Strategy. The Commonwealth does not have a role in funding anything that has a narrower focus, such as the clinical services for the people in a particular town; this is the responsibility of the relevant State and local authorities.

It is important to know this distinction so that emphasis and personal resources are not wasted on targeting the wrong area.

The National Mental Health Policy and Plan

The adoption of the National Mental Health Policy (1992) by all the States and Territories has given much more cohesiveness to the provision of uniform services throughout the nation. The Policy emphasises the need to develop nationally consistent mental health legislation and was developed in response to concern about the human rights of people with mental illness, and widespread dissatisfaction with inadequate, under-funded and often non-existent services. Other influences were the international trends in deinstitutionalisation of the mentally ill and the introduction of various community mental health care models.

In 1992 the first National Mental Health **Plan** was developed to provide specific strategies to assist in the implementation of the Policy. The Plan needs to be read in conjunction with the National Mental Health Policy (1992). The broad aims of the Plan are to:

- Encourage a national approach to mental health policy and service delivery,
- Strengthen the impetus for reform of mental health services,
- Provide a mechanism for addressing agreed priority issues.

The National Mental Health Plan (1992) was designed to have an operational life of five years. In 1998 a new National Mental Health Plan was developed to continue the work of the first Plan, while keeping its focus.

Consumer participation in mental health decision-making processes

One of the strategies of the first National Mental Health Plan was an agreement to provide for ongoing mechanisms for consumer and carer input into mental health decision-making processes through:

- Each State/Territory establishes and maintains a mental health consumer advisory committee which is representative of the range of mental health consumers and carers. The role of the advisory committee is to provide advice to both the relevant government minister, and the chief executive officer of the agency. These committees have become known as State **Consumer Advisory Groups** (CAGs).
The Commonwealth establishes and maintains a **National Consumer Advisory Group (NCAG)** with a similar role to that for the State CAGs, but reporting to the Commonwealth rather than to the State.

Some States have also developed local mechanisms for involving consumers and carers in the development of services. For example in Queensland, most mental health services have links with local Consumer Advisory Groups which fulfil a role similar to that of the State and national CAGs, except that they are not Ministerial advisory committees.

### The mental health workforce

Mental health service provision in Australia is firmly based on the ‘medical model’ and, as such, is controlled by the medical profession. At the top of the hierarchical structure are the psychiatrists (medical practitioners specialising in psychiatry). There are, of course, those who disagree with the medical model, especially now that Australia is committed to providing community-based services that reflect the wide range of contributors to mental illness and mental health. Managers and multi-disciplinary workers (workers from a range of mental health disciplines) may be employed throughout services. However, it can be argued that while the person in charge is a medical practitioner, the service is based on the medical model.

### National structure

Nationally, mental health services come under the portfolio of the Federal Minister for Health. Responsibility is delegated to the Commonwealth Department of Health and Family Services. Within this Department is the Mental Health Branch, overseen by a Director. In broad terms, the role of the Mental Health Branch is to develop national policy, facilitate the implementation of national policy and allocate funding to various projects of national significance. The Branch does this through collaboration with the various State and Territory mental health branches, Consumer NCAG and other key stakeholders. In addition to the Director, other staff include project workers, policy writers, consultants and support staff.

Advocacy and lobbying activities, which can be appropriately targeted at the Commonwealth Mental Health Branch, include those of national significance and those which cannot be dealt with by State branches. An example of this is lobbying for increased funding for projects directed at indigenous mental health consumers and carers. Issues about non-compliance with National Standards by State and Territory mental health branches may be directed to the Commonwealth branch.

### State structures

State and Territory mental health services are generally the responsibility of the various health ministers. This responsibility is generally delegated to the health departments staffed by government workers (or bureaucrats), although some States may operate their mental health services through other departments, such as community services. Within each of these departments there are mental health branches with the responsibility of developing and overseeing the policies required. These branches are known by various names around the nation, such as Mental Health Unit in Queensland and Mental Health Division in Western Australia.
Much of the work of these ‘branches’ is concerned with putting in place the National Mental Health Strategy components such as the National Standards for Mental Health Services. It is important to recognise that the branches are the policy makers but not the ‘bosses’ of the local services and cannot get involved in day-to-day operation of the local services. A problem can arise when a local service refuses to comply with a certain policy, and comes up with a lot of reasons why it can’t or won’t comply.

Mental health branches are often run by a manager, often in conjunction with a clinical director who is a psychiatrist. Problems can and do occur in regard to issues of power and control. The provision of health care is extremely expensive and governments throughout Australia are concentrating on ways to reduce costs. This approach to health care is sometimes referred to as ‘economic rationalism’. However, costs can only be reduced so far before the quality of services must begin to suffer. As a result there is always tension between the managers, who are concentrating on keeping within the budgets supplied by government, and mental health service providers, who are concentrating on delivering what is needed by people living with a mental illness.

Branches are staffed by an array of workers, including mental health professionals working as policy writers, as well as people from management and financial backgrounds. Branches generally don’t employ a large number of full-time workers, but may employ project officers for specific tasks. These are often recruited from workers currently in the public service system, and may be mental health workers seconded from a local mental health service.

State and Territory branches are also responsible for allocating funding to the various local mental health services as well as to non-government community mental health organisations. Most of these organisations receive the majority of their funding in this way. State and Territory mental health branches are appropriate targets for advocacy and lobbying on matters of State policy and requests for funding. They can sometimes assist in applying pressure to local mental health services that are obviously violating mental health standards.

Local mental health services

Most local mental health services are directed by psychiatrists. A recent trend, consistent with the push for cost-effectiveness, is the introduction of managers to mental health services. Managers are business-minded administrators whose job is to manage the organisational aspects of the service; they may or may not have experience in mental health service provision. Another recent trend in some localities is to employ service development officers, whose role is to implement services consistent with the National Mental Health Plan. The rest of the staff of local services are generally clinical and support staff.

Another recent trend is the employment of consumer consultants by some of the more progressive services. Local services should also have an appropriate mechanism for involving consumers and carers in the development and delivery of services. This needs to be considered a part of the local service, although a local consumer advisory group may have many other functions, and certainly does not come under the control of the service.
Local services are the ‘coal face’ of service provision. In relation to advocacy and lobbying, many situations can (or should) be sorted out at the local level. However, the local service may respond by saying that the problem is a result of policy or funding over which it has no control. It is beyond the scope of the resources in this Kit to detail the responsibilities of local services, State and national branches. The references provided at the end of this section provide the reader with the appropriate sources to locate this information.

It is important that the individual or group is clear about which situations involve the local service, the State and the Commonwealth. As each State/Territory is different, and each service has individual policies, the best way to find out this information is to invite representatives from the local service to come and explain its decision-making process. Request the service to write this information down and provide it as handouts for all members of the group. (Also see 5.1: Strategic thinking in targeting the message and 5.6: Lobbying in Skills, Strategies and Tools.)

**Mental health services – what consumers and carers can expect**

Until the 1990s, each State and Territory within Australia made its own decisions about mental health care, resulting in a lack of national consistency. In 1992 the first National Mental Health Policy and Plan was put forward by the Commonwealth Government. Together with the Statement of Rights and Responsibilities these form the National Mental Health Strategy. Each State and Territory is required to follow the guidelines encompassed in the Strategy to improve the lives of people diagnosed with a mental illness.

The *Mental Health Statement of Rights and Responsibilities* (1991) aims to ensure that consumers, carers, advocates, service providers and the community are aware of their rights and responsibilities and can be confident in exercising them (p1). A key point made in the Statement refers to the education of people who are likely to provide services to people with mental health problems. For example, it is expected that teachers, police, welfare workers, clergy and other non-health professionals will be sufficiently educated to enable them to recognise and refer people with mental health problems.
The aims of the Strategy are to:

● Promote the mental health of the Australian community,
● Prevent the development of mental health problems and mental disorders where possible,
● Reduce the impact of mental disorders on individuals, families and the community,
● Assure the rights of people diagnosed with mental disorders.

These aims are to be achieved in a number of ways. Firstly, mental health is being mainstreamed within general health care as a strategy meant to reduce stigma associated with mental illness. As a result, general rather than psychiatric hospitals are meant to provide acute (severe, but short-term) care services for people diagnosed with mental illness. This is an attempt to ‘normalise’ mental health problems and treat them like any other illness. If a person has a chronic (long-term) illness or disability, he or she needs the symptoms treated, and needs to learn how to deal with the issues that develop as a result of having that particular illness or disability, regardless of whether the diagnosis is a physical or mental illness.

Secondly, integrated networks of different services must be provided if community-based care is to work. The provision of these networks is outlined in the Strategy. The Strategy also addresses the following key issues: consumer rights; the provision of integrated mental health services; intersectoral links; legislation; workforce reform; monitoring and accountability procedures and the requirements of special needs groups, such as people from non-English speaking backgrounds or of Aboriginal and Torres Strait Islander descent.

Want to find out more?

To find out how your local mental health service is implementing the National Mental Health Strategy, invite a senior person from the service to come and explain in detail.

At the same time, many other factors are involved in health care provision. For example: consumers are encouraged to take more responsibility for their own health and health care; consumers are having more of a say in their treatment; there is a strong focus on health promotion; community resources are being developed and there is a focus on interdisciplinary collaboration between professional groups (this means that workers from different professions, such as social workers and psychiatrists, work with each other as equals and offer the skills from their specific backgrounds).
Comprehensive mental health services are now being set up throughout Australia. To provide the least restrictive alternative for consumers, many mental health problems need to be managed within the community and the availability of comprehensive mental health services enables this to occur. As it is estimated that only five percent of people with mental health problems require inpatient services, developing community mental health services is vital.

According to the National Mental Health Plan the following services need to be included within a comprehensive model:

- **Inpatient unit**
  - To provide acute short-term care for patients who require stabilisation and/or may be a danger to themselves or others – ideally a small unit attached to a general hospital.

- **Crisis intervention**
  - To provide short-term intensive care in the community with the aim of resolving the crisis and preventing hospitalisation.

- **Assertive treatment teams**
  - To provide long-term follow-up of people with mental health problems living in the community – to provide a wide range of services to meet the person’s needs, including the reduction of symptoms; maintenance of substance-free lifestyles; maintenance of safe, affordable housing; establishment of a supportive social network; minimisation of involvement with the criminal justice system; choosing, getting and keeping a job; assuring adequate income and improving satisfaction with life.

- **Rehabilitative services**
  - To teach the person a wide range of skills for living in the community, including the facilitation of employment opportunities.

- **Accommodation services**
  - To provide adequate housing.

People with identified mental health problems usually have a case manager whose role is to facilitate the person’s needs being met. Some consumers, however, do not like the term ‘case manager’ because it suggests that they are a ‘case’ that needs to be ‘managed’. Given the history of mental health care, this reaction is understandable. Some services prefer to use the term ‘individual service plans’.

The significant mental health reform that has taken place has numerous implications for a wide variety of stakeholders. Mental health services accessible to the public are required to provide services to people who have been diagnosed with a ‘mental illness’. But what is a ‘mental illness’? People who have been diagnosed as living with one form only a small part of a much larger client group. It is acknowledged that approximately one in five people within the community experience mental health problems serious enough to warrant intervention.
However, many people do not meet the criteria of mental illness as laid down by specific mental health services. This means there are many people within the community whose needs must be met outside of the public mental health system. In addition, the move to community-based systems of care has meant that, even for people with diagnosed mental illnesses, mainstream generalist services and the wider range of community services are of paramount importance. All of this has necessitated the expansion of the role of the community, generalist services and the non-government sector. Similarly, other government departments, such as those concerned with family, youth community services, public works and housing, have a role to play in the provision of disability services, employment and accommodation.

Underpinning any reform is a philosophical position that informs the process. In mental health reform, a social integration philosophy is fundamental. Such a position acknowledges the rights of every person to have quality of life and their mental health needs met within the community in which they reside. People living with mental health problems have the same rights as every member of the community. Traditionally, however, this has not been the case and obstacles/challenges now exist which affect the reform process. For example, stigma within the community is an historical legacy that hasn’t helped the reform process.

The changing nature of service delivery can threaten some health professionals and service providers. The roles of carers of people living with mental health problems and consumers have changed to become much more active and participatory. In addition, health professionals, consumers and carers have been thrown together in new ways that require sensitive negotiation. Non-government organisations and the wider community are taking on much larger roles in mental health service provision. There is a shared responsibility amongst a few government departments for various aspects of comprehensive mental health care that necessitates much greater cooperation than was needed in the past.

The table below outlines the different assumptions that underlie the changing nature of service delivery. The implications are that the role of the mental health worker requires reorientation as follows:

- Shifting from the role of caretaker to the role of helper,
- Listening to and supporting people’s dreams and hopes,
- Supporting people through the process of using community services as guide, bridge-builder and community connector,
- Assisting with skills and contacts,
- Identifying and minimising behaviours that set people apart.
The changing nature of service delivery

<table>
<thead>
<tr>
<th>Mental health worker</th>
<th>Old way</th>
<th>Current service delivery</th>
</tr>
</thead>
<tbody>
<tr>
<td>How do workers perceive the person with a mental illness?</td>
<td>as a disabled client</td>
<td>as a person</td>
</tr>
<tr>
<td>How do workers define this person’s needs?</td>
<td>he/she has deficiencies</td>
<td>he/she has capacities</td>
</tr>
<tr>
<td>How do workers see the community?</td>
<td>as an obstacle (fear, prejudice, ignorance, rejection)</td>
<td>as a resource (understanding, awareness, acceptance, inclusion)</td>
</tr>
<tr>
<td>Who’s in charge?</td>
<td>top down (policy; regulations to guide professionals)</td>
<td>consumer self-determination (circle of support; resources controlled by person)</td>
</tr>
<tr>
<td>What is the worker’s role?</td>
<td>service provider</td>
<td>enabler, supporter</td>
</tr>
<tr>
<td>What is the worker’s vision of the future for the person with the mental illness?</td>
<td>more of the same (clienthood)</td>
<td>citizenship (hopes, dreams, opportunity)</td>
</tr>
</tbody>
</table>

Adapted from Curtis, L, (1994)

National Standards for Mental Health Services

In December 1996 the National Mental Health Working Group of the Australian Health Ministers’ Advisory Council (AHMAC) endorsed the National Standards for Mental Health Services. The Standards are designed to fulfil several roles: they can be used as a blueprint for the development of new services or as a guide to service enhancement and continuous quality improvement; they can be used as a tool to inform consumers and carers about what to expect from mental health service and as a checklist for service quality; and they can assist consumers and carers to participate in a service’s planning, development and evaluation processes.

There are 11 National Standards for Mental Health Services:

**Standard 1: Rights**
The rights of people affected by mental disorders and/or mental health problems are upheld by the MHS (Mental Health Service).

**Standard 2: Safety**
The activities and environment of the MHS are safe for consumers, carers, families, staff and the community.
Standard 3: Consumer and Carer Participation
Consumers and carers are involved in the planning, implementation and evaluation of the MHS.

Standard 4: Promoting Community Acceptance
The MHS promotes community acceptance and the reduction of stigma for people affected by mental disorders and/or mental health problems.

Standard 5: Privacy and Confidentiality
The MHS ensures the privacy and confidentiality of consumers and carers.

Standard 6: Prevention and Mental Health Promotion
The MHS works with the defined community in prevention, early detection, early intervention and mental health promotion.

Standard 7: Cultural Awareness
The MHS delivers non-discriminatory treatment and support which are sensitive to the social and cultural values of the consumer and the consumer’s family and community.

Standard 8: Integration

8.1 – Service Integration
The MHS is integrated and coordinated to provide a balanced mix of services which ensure continuity of care for the consumer.

8.2 – Integration Within the Health System
The MHS develops and maintains links with other health service providers at local, State and national levels to ensure specialised coordinated care, and promotes community integration for people with mental disorders and/or mental health problems.

8.3 – Integration with Other Sectors
The MHS develops and maintains links with other sectors at local, State and national levels to ensure specialised coordinated care and promotes community integration for people with mental disorders and/or mental health problems.

Standard 9: Service Development
The MHS is managed effectively and efficiently to facilitate the delivery of coordinated and integrated services.

Standard 10: Documentation
Clinical activities and service development activities are documented to assist in the delivery of care and in the management of services.

Standard 11: Delivery of Care – Principles Guiding the Delivery of Care

11.1 – Access
The MHS is accessible to the defined community.

11.2 – Entry
The process of entry to the MHS meets the needs of the defined community and facilitates timely and ongoing assessment.
11.3 – Assessment and Review
Consumers and their carers receive a comprehensive, timely and accurate assessment and a regular review of progress.

11.4 – Treatment and Support
The defined community has access to a range of high quality mental health treatment and support services.

11.4.A – Community Living
The MHS provides consumers with access to a range of treatment and support programs which maximise the consumer’s quality of community living.

11.4.B – Supported Accommodation
Supported accommodation is provided and/or supported in a manner which promotes choice, safety and the maximum possible quality of life for the consumer.

11.4.C – Medication and Other Medical Technologies
Medication and other medical technologies are provided in a manner which promotes choice, safety and the maximum possible quality of life for the consumer.

11.4.D – Therapies
The consumer and the consumer’s family/carer have access to a range of safe and effective therapies.

11.4.E – Inpatient Care
The MHS ensures access to high quality, safe and comfortable inpatient care for consumers.

11.5 – Planning for Exit
Consumers are assisted to plan for their exit from the MHS to ensure that ongoing follow-up is available if required.

11.6 – Exit and Re-entry
The MHS assists consumers to exit the service and ensures re-entry according to the consumer’s needs.

Copies of the National Standards for Mental Health Services can be obtained through the Director of Mental Health in each State and Territory, or the Mental Health Branch of the Commonwealth Department of Health and Aged Care by phoning 02 6289 8396 or by writing to: MDP 37 GPO Box 9848 Canberra ACT 2601.
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The higher education system

In 1994, the National Community Advisory Group on Mental Health (NCAG) undertook consultation workshops with consumers, carers and the community. It considered priorities for implementing recommendations contained within the *Report of the National Inquiry into the Rights of People with Mental Illness*. The report of the consultation workshops included the statement:

‘The overwhelming belief of workshop participants was that they experienced more stigma and discrimination from mental health professionals than from any other sector of society. It should be noted that this stigma and discrimination occurs within the context of an inadequate and inappropriate system of mental health care.’ (p23)

Consumers and carers have consistently said that this inadequacy and inappropriateness stems, in part, from the preparation of health professionals through the higher education system.

The mental health professions

There are five major health professional groups working within the mental health system:

- Nurses,
- Occupational therapists,
- Psychiatrists,
- Psychologists,
- Social workers.

Each of them becomes qualified for professional practice through firstly undertaking a university course.

Nurses

Only in the last five to ten years has the preparation of nurses to practice in mental health settings moved from dedicated on-the-job education and training to university settings. This shift occurred when basic nursing education and training for all nurses started being provided through a single comprehensive nursing program. This now means that all graduates of the basic nursing course are permitted to practice in any setting, including mental health, without additional study. There are no longer specific psychiatric or mental health nurses in basic level training.
When nurses graduate from the university they must register with their respective State/Territory nursing registration body before they can practice.

The basic university program for nurses introduces mental health concepts. The students also receive some ‘field placement’ in mental health service settings.

Some mental health services provide an extensive orientation to new graduates before considering them to be ‘qualified’ practitioners. This varies between States/Territories and services.

Postgraduate courses in mental health nursing are being made available to those nurses who wish to gain specialist qualifications.

**Occupational therapists**

Occupational therapists undertake a university education and training program that produces occupational therapists to work in any setting. Many of the courses include compulsory or elective field placements in mental health settings.

Upon graduation, occupational therapists may be employed in mental health settings on the basis of their basic qualification.

**Psychiatrists**

Before commencing education and training in psychiatry, the person will have completed a medical degree. Psychiatry is a university-linked program provided through extensive field placement supported and supervised by senior psychiatrists. Psychiatrists qualify by successfully completing the requirements as set down by the Australian and New Zealand College of Psychiatrists. This includes on-the-job learning and demonstration of academic competence.

**Psychologists**

Psychology is an academic, non-clinical course at undergraduate level. With a four-year degree and two years of supervision, psychologists are eligible for registration to practice and officially use the title ‘psychologist’ in each State and Territory. The Australian Psychological Society (APS) prescribes that preparation for clinical practice should be at masters level or above. From the year 2000, full APS membership will reflect this requirement. All masters courses in clinical psychology include a minimum of 1,000 hours of field experience together with theoretical content.

**Social workers**

As with occupational therapists, social workers undertake a generic university education and training program, possibly including elective field placements in mental health settings.

The basic qualification is sufficient for employment in mental health settings.
Participation in professional learning

Consumers and carers have for some time expressed their dissatisfaction with the way professional health workers view them. Health professionals have adopted various ‘models’ of mental illness, mental health, medical/psychological/social intervention and rehabilitation. These are rarely seen by consumers and carers as capturing an up-to-date view of the way they experience mental illness and recovery. The basis of health professional learning is mainly theoretical with little opportunity for incorporating the richness of the consumer and carer experience.

Universities have begun to respond to these concerns. There is evidence of some limited contribution by consumers and carers to the learning of health professionals. The form of this contribution, however, often appears tokenistic. Commonly, carers and consumers have been invited to ‘tell their story’, to give some form of account of their experience of living with a mental illness. (Also see: Some forms of consumer and carer participation.) These sessions are usually well received. Consumers and carers who tell their stories tend to experience satisfaction and a sense of purpose and value. The students are generally responsive to, if not in awe of, the stories told. There seems, for many, to be a reserved acknowledgement of the trauma of injustice that exists in most consumer and carer experiences. It seems to disappear in most students before they graduate.

The opportunities

There are many opportunities for consumers and carers to participate in the learning of pre-qualified professionals – in the classroom, during work experience, in formal student assessment and through course design and evaluation.

Participation in the classroom can go well beyond the face-to-face presentation or interaction with students. Influencing the way health professionals learn is achievable through participation in design, delivery and evaluation of the learning experience.

Design of the learning experience

- All courses go through a process of approval. The steps differ from university to university. They usually incorporate some initial design – somebody has to put pen to paper to develop the structure and content of the course – and agreement from a range of people before the course can run. There is usually some sort of course committee.

- There is usually flexibility in the way courses are provided. Heads of departments, course coordinators and lecturers all have some capacity to shape the way the course is run, provided it meets the learning objectives of the course.

- To varying degrees, learning for the five professional groups blends classroom study with field experience. Psychiatrists tend to be exposed to mental health settings the most. For others, placement in mental health settings may be an elective option from a number of, perhaps more attractive and glamorous, alternatives. Sometimes individual placements are negotiated by each student; sometimes the university negotiates ‘block’ placement.

- Universities have processes of policy decision-making. Consumers and carers can influence course design and delivery policy through engaging in these processes.
Delivery of the learning experience

- Consumers and carers may continue to participate, by invitation, presenting their story to students.
- Individuals can be employed as casual teaching staff, designing and presenting specific units or contributing to parts of units.
- Individuals can be engaged to facilitate or co-facilitate discussion groups or tutorials.
- Individuals or groups can design and undertake workshops on particular topics. These are particularly useful for simulating real experiences and for role-play.
- Groups can engage students in participatory exercises. Games like ‘Lemon Looning’, a board game developed within the Lemon Tree Learning Project, are particularly useful in this regard.
- Individuals or groups can work with field placement supervisors to design particularly useful consumer- or carer-focused experiences.
- Individuals or groups can assist field placement supervisors in the process of gaining useful experiences for students through, for example, discussions, reflection and mentoring.
- Consumers and carers are well placed to contribute to the delivery of specialist ‘bridging’ programs offered by some mental health services to students.

Evaluation of the learning experience

- Consumers and carers can assist in the design, application, analysis and reporting of course evaluation.
- Evaluation may be undertaken of specific learning sessions, units, field placements or whole courses.
- Consumers and carers can be part of an evaluation team or provide evaluation of student learning from their own perspective.

The constraints

There are a number of constraints to participation in the higher education sector that need to be considered. These include:

- The higher education system is a collective of individual institutions. Each university has its own culture, its rules of conduct, its traditions. Some universities have a national structure that influences its courses and processes, for example, the Australian Catholic University. There is no single repository of information for all universities on how consumers and carers can negotiate the system. It is clear, however, that substantial negotiation is usually required.
- There are some enlightened university staff who recognise the importance of consumer and carer participation in professional learning. These individuals are leading the way in opening doors for consumer and carer participation. These are usually independent actions undertaken outside of formal recognition by the faculty or university of its existence or worth. Often the continuance of these activities is reliant upon the individual’s ongoing presence.
Those university staff who have thought about consumer and carer participation report their own difficulties in not knowing how to access consumers and carers who are organised and capable. Participation in some instances has occurred through a chance meeting with a consumer or carer.

Comprehensive professional learning programs will not readily find a place for specific mental health consumer and carer participation. Involvement in postgraduate specialities provides greater flexibility and relevance. However, exposure of postgraduate students to potentially damaging existing mental health services, practices and attitudes will have already commenced.

Consumers and carers may anticipate being paid for many aspects of their contribution to health profession learning. Some university administrators may not consider this appropriate. Most course administrators are restricted in their freedom to identify and allocate funds in this way. There will always be a limit on finances available for external contributions. Universities are required to generate some of their own funding and, as a result, may be increasingly careful about spending.

Not all universities have well-structured evaluation mechanisms. Where they exist they may be tied to learning objectives which have not been shaped by consumer and carer input.

Where consumers and carers have participated, the level of support available from the university, including feedback and debriefing, is variable.

Some university staff who engage with consumers and carers in participatory activities have voiced their desire to negotiate their own suitable supervision before participation commences.

A number of professional interests also have a stake in course development and course outcomes. Some are highly influential, others less so. They include the various professional organisations:

- Australian and New Zealand College of Mental Health Nurses
- Occupational Australia Inc.
- Royal Australian and New Zealand College of Psychiatrists
- Australian Psychological Society
- Australian Association of Social Workers

The respective State/Territory professional registration bodies also influence some professional course designs. This is particularly true of nursing.

In some courses, the worth of consumers and carers as participants may not be acknowledged even at a fundamental level.

Consumers and carers may be seen to lack credibility. The value of their experience may not be recognised where they do not have their own formal teaching or professional qualifications.

Course design may severely limit the opportunities for any type of external contribution, let alone that of consumers and carers.
The central challenges

For consumers and carers to experience genuine participation in the shaping of positive attitudes, values and practices through the higher education sector, a number of challenges will need to be addressed:

- Having consumer and carer contributions legitimised as a required and integral part of preparation of health professionals,
- Having the value of consumer and carer participation respected by universities, professional organisations, registration bodies, national and State/Territory policy-makers,
- Being organised and capable of accepting the invitations to participate as they arise,
- Being organised to sustain the concerted effort required to influence traditional, institutional thinking and behaviour of universities and professional organisations,
- Being skilled in a range of ways of participation,
- Taking the issue of participation to the higher education sector – universities have little impetus to do the inviting themselves,
- Being placed as a contributing partner between the higher education sector and service providers in the provision of clinical field placements for students,
- Identifying, proposing and engaging in meaningful evaluation of the higher education sector from a consumer and carer perspective,
- Being able to assure teaching staff that consumer and carer involvement in the learning of health professionals is ethical and does not compromise anyone’s position,
- Being able to assure industrial organisations that payment of consumers and carers for sessional work does not restrict the employment of teaching staff,
- Identifying, for each university, who has authority to make which decisions.

Non-clinical mental health workers

As well as the five health professional groups, the core mental health system workforce includes large numbers of non-clinical mental health workers. These are sometimes described as psychiatric disability support workers and are usually employed in non-government mental health services.

The non-government mental health sector has grown as an important contributor to the tapestry of comprehensive mental health service delivery. Non-government organisations increasingly attract people with health profession qualifications and others with higher education qualifications, as well as unqualified people.

Some vocational education and training facilities (TAFEs) offer diploma courses to the industry. There is now a nationally accepted standard that supports learning in this sector – The Mental Health Work (Non Clinical) National Competency Standards. These Standards have been developed in consultation with consumers and carers.

Where these courses have been offered, consumers and carers have tended to participate in their design, delivery and evaluation.
References


The broader community

Introduction

Mental illness is primarily considered by the broader community to be a ‘taboo’ subject. It is something people do not talk about, do not admit to having and are unwilling to disclose to ‘non’-mentally ill people. Though shrouded in misunderstanding and innuendo, mental illness directly affects one in five people in the community. Countless more go undiagnosed because of fear, stigma and misunderstanding.

This section of the Kit is designed to increase knowledge about parts of the community that consumers and carers may involve in advocacy and community development issues. This does not mean that advocacy may be limited to only these parts of the community. Consumers and carers may identify many other targets of advocacy, community development and community partnerships. The community groups discussed here are those that consumers and carers say affect them to the greatest extent.

The nature of stigma and intolerance

Stigma, stereotyping, intolerance and discrimination are concepts well known to, and experienced by, many people with mental illness, as well as those who care for them.

The word stigma is Greek for ‘mark’ or ‘brand’ and has come to mean ‘a mark or blemish on one’s reputation’. A stereotype is an oversimplified image of a group of people who fall (or are pushed) into a particular category. The difference between stigma and stereotype is that a stigma is always negative, whereas a stereotype can be positive.

Stigma and stereotyping put individuals into groups which divide them from the broader community. Marginalised groups often encounter prejudice as a whole or as individuals. Often prejudices can be irrational and conflicting. For example, a prejudiced person may say that people from a particular country are both ‘ignorant and sly’.

Stigma and negative stereotyping lead to discrimination, which builds barriers between people who conform to ‘socially acceptable behaviours’ and those who do not. Stigma and negative stereotyping also build barriers between groups which do not conform, resulting in inequality between marginalised groups. Discrimination can lead to reduced access to basic human rights such as employment, housing, police protection. Discrimination can have an enormously detrimental effect on a person’s self-esteem, confidence and ability to function in society.

Most people who live with mental illness and their carers can relate stories about being discriminated against because of incorrect and prejudicial opinions about their mental health experiences. These discriminations force those who have been diagnosed with ‘long-term mental health problems’ to accept their ‘fate’, as decreed by the medical profession, and ‘become their disorder’. Those that have one or few episodes of mental illness and re-enter the broader community often live in fear of being ‘found out’.
How do stereotyping and stigmatising develop?

It is important to consider how stereotypes have developed in the wider community. A first meeting with a person looking or behaving ‘illogically’ or ‘differently’ from known appearances and behaviours can produce anxiety. People often stereotype others to reduce their own anxiety; it provides some comfort to be able to bunch others into ‘familiar groups’, rather than try to understand their ‘difference’.

Stereotyping of marginalised groups is frequently promoted by the media and entertainment industries. The influence the visual media, such as television and movies, have in shaping an individual’s knowledge is powerful. The media and popular culture often portray a sensationalised or distorted picture of what it may mean to have a mental illness. For example, movies are made for the entertainment value they provide. They can be irresponsible in their portrayal of people living with mental illness for the sake of ticket sales or out of sheer ignorance.

Educating the community and improving understanding of mental health issues in society is vital to reduce stigma, stereotyping, prejudice and discrimination. This can be achieved effectively through advocacy and community development programs and public education campaigns.

Who makes up the broader community?

Everyone. Society is a diverse and complex structure. When considering changing community attitudes and reducing stigma it is difficult trying to pinpoint where to start. Certainly the media and popular culture (television and movies) play an integral part in shaping public opinion. But there are many other groups within the community which can be targeted to bring about a positive change in understanding mental illness.

Some specific groups, with a widespread influence on the general community and, therefore, significant in self-advocacy, include:

- The media,
- The police service,
- Schools and educational institutions,
- Local councils,
- Community groups and non government agencies,
- Religious groups,
- Government agencies,
- Health professionals.

These are some sections of the community which have been identified by many consumers and carers as needing greater knowledge about the realities of living with a mental illness. These sections are just a starting point. There are, of course, many others.
Developing community partnerships

The development of community partnerships begins with the establishment of individual relationships between key people. This may begin with the initial meeting between members of the group and the particular community agency (for example, the local police service). At this meeting the group needs to clearly and succinctly state the reasons for wanting to establish a relationship with the agency and the proposed outcomes/benefits for both parties. It is important to listen to the story of the community agency, to find out ‘where they are at’, and to find out what the agency perceives the group can do in return. In developing links with the broader community, the group needs to be in a position to offer something to the other agency, as well as to expect assistance in return. This is the essence of community partnerships. The community agency will want to feel confident that the group understands, or is willing to understand, its issues, resources, structures and problems.

Sometimes people use this sort of meeting to air difficulties and problems and end up getting a bit off the track. However, listening to the agency’s story can go a long way towards enabling the initial contact person to feel at ease, to develop trust and to be receptive to what the group has to say. By respecting the agency’s story, the contact person is more likely to respect the group’s story. The establishment of a good rapport provides a solid framework to build formal liaison links.

The media

In this technological age, the various kinds of media have enormous potential to affect the formation of attitudes, beliefs and knowledge. The community relies on the media to provide information on what is happening locally, throughout the country and in the world. This power makes the media the ideal forum through which to provide the community with positive and accurate information about mental illness, with the aim of reducing stigma and negative attitudes. On the other side of the coin, if the media provides incorrect information, then the community’s negative attitudes may be reinforced and increased.

The community receives information about mental illness from a number of media sources. Television shows such as ‘soapies’, the news and current events are possibly the most significant sources. Television coverage of news and current events has an especially powerful affect on public perceptions about mental illness. It is common to see the evening news reinforcing negative stereotypes about mental illness and people with mental illness.
The media presents many differing points of view about mental illness to audiences. These range from comical, crazy objects of ridicule and people to be feared, to more in-depth and realistic representations that remind society mental illness is a serious condition for which people need understanding, support and assistance. The media have a responsibility to promote an accurate and sensitive portrayal of mental illness.

Advocacy and community development groups can work towards achieving positive change. For change to occur there must be both education and challenge. The media is driven by public demands: if the media receives feedback from their audience calling for sensationalism, then they will give it to them. Those working in the media may not even know what is inappropriate or objectionable without feedback from their audiences. The media are only likely to make changes to their style of reporting and presenting if there is a clear demand for change from their audiences and indications of widespread dissatisfaction with what they are doing.
Working with the media

One media officer working with a community mental health association reports that, in 1996, journalists only wanted to write about the ‘gory’ details of what it was like to have a mental illness. A reporter from a national prime time television program wanted the officer to ‘get a schizophrenic with talent to put on screen’. In 1996 she reports it was virtually impossible to interest journalists in writing positive stories about people who cope with their mental illness, re-enter society and live productive lives.

Through constant lobbying by the mental health community, the situation has changed in Queensland. Media officers now report a willingness on the part of journalists to present the truth, both positive and negative. Some credit for these positive changes go to an innovative project developed and hosted by the Queensland Association for Mental Health, with a representative assessment panel comprising various media and mental health representatives. This project, known as the 1997 Mental Health Media Awards, provided awards for positive, accurate and balanced reporting of mental health issues in the Queensland print media during the 1996/97 period.

Obtaining support from the media

There are many ways the media can positively influence the community’s attitude towards people with a mental illness. By supporting advocates in fighting for more resources to be allocated to preventative work in mental health, better training for mental health professionals, more research into causes and treatments and more support for community education, the media can affect a positive change in the way people deal with people with a mental illness.
Capturing media attention requires some knowledge of the way the media works. It is important to understand the media’s motivation in reporting a story or event. Too often journalists want to write a story that will get them ‘the splash’ – the cover story – a much coveted and competed-for prize.

Journalists question how they will use the information and its context. There are many incidents of people being asked to ‘share their story’ regarding their illness. It takes great courage for a stigmatised person to speak publicly and it is devastating when they are misrepresented and left feeling exposed and vulnerable. It is important for a prospective interviewee to ask questions such as:

- What is the motivation for the story?
- What is the format for its presentation?
- Which audiences will read/hear/see it?
- Can it be previewed prior to publication/presentation?
- What recourse can be taken if the story is inaccurate?

Always weigh up the personal cost when considering sharing a personal story and always try to ensure some control when working with the media.

(Also see 5.5: Working with the media in Skills, Strategies and Tools.)

Many mental health groups and organisations benefit from issuing ‘media releases’ to newspaper journalists and television and radio reporters who comment on topical issues or events. Media releases can also be used to offer a different perspective on negative reports. Letters to the editor of a newspaper are another effective means of presenting an opinion to a wide audience.

A new player has entered the field of media: the Internet. Many mental health organisations have ‘home pages’ which can reach a wide audience with up-to-date information. Mental health ‘chat rooms’ can provide advice, information, support or just someone to talk to who may understand. (Also see: Engaging Networks and Organisations.)

The media is a powerful tool, and while there is a cliché that ‘no press is bad press’, it is important to use the media strategically and not get misrepresented in the process.

The police service

The police have the unenviable and frequently difficult job of enforcing the law. The police are often marginalised by the community. There is a stigma attached to being a police officer often resulting in stereotyping in a negative light. The suggestions provided above under ‘Developing community partnerships’ on page 105 are particularly appropriate to police. If the group is willing to listen to the conditions under which police officers work and to understand where the police ‘are coming from’, then the police are more likely to listen to those involved in advocacy activities.

On occasion, the police are required to deal with a person who has a mental illness. A lack of knowledge and training in mental health can lead to tragic consequences. Often police are unaware they are dealing with someone who has a mental illness.
They may not be trained to recognise the symptoms of an illness and/or that medication can cause a person to appear drunk or under the influence of narcotic drugs. Many homeless people who are refugees of the ‘deinstitutionalisation’ process (that is, discharged from hospitals without the provision of adequate community supports) also attract the attention of police who can be unaware of the person’s circumstances.

It is often not recognised by the wider community that a person’s behaviour may be the result of an illness, and generally it is the police who are called when someone is concerned about another person’s inappropriate behaviour. A situation is often exacerbated when the ill person is approached by the police in an aggressive or threatening manner. There are many reports from mental health consumers of the emotional trauma and physical harm resulting from police intervention.

Police receive very little training about mental illness. The majority of training received is generally only about police obligations under the relevant Mental Health Act in that State or Territory. Some police report they have not been given the skills or knowledge to intervene in an effective, supportive manner with a person who is experiencing acute symptoms of mental illness.

Each Australian State and Territory has a different Mental Health Act that governs the involuntary detainment of a person deemed to be ‘at risk to him/herself or to others’. Police can be required to execute a warrant to take someone for assessment or treatment, or can be called to a situation where it is believed that a person requires psychiatric intervention. This is an unpleasant scenario for everyone involved. Police say they are often not informed of the clinical nature of the situation and feel like the ‘meat in the sandwich’ between the ill person and medical help.

Towards a positive relationship

There are many ways that mental health consumer groups and professionals can work with police to improve their respect for the dignity of people with a mental illness. For example, the use of an unmarked police car when issuing a warrant under the Mental Health Act can reduce embarrassment or the implication that the person has been ‘bad’.

Meeting face-to-face with people who have a mental illness in a period of wellness can give encouragement to police by demonstrating that the work they undertake in getting ill people to treatment is vital and frequently has a positive outcome. Briefing police officers prior to attending situations in which a mentally ill person is involved, as well as debriefing by mental health professionals after a tense incident, can improve the police relationship with people with a mental illness and their carers, as well as the confidence of the police to effectively deal with such situations.

How to involve police in advocacy and community development

The group can start by finding the right person to approach. The Senior Sergeant at the local police station is a good place to start. This officer controls staffing and allocation of resources and has a good knowledge of working conditions, as well as being the link to senior management.
Police have a focus on ‘community’ and most Senior Sergeants are likely to be willing to sit down and talk with community groups. Police services have numerous community programs designed to raise the image of police. Examples include Police Youth Clubs and the ‘adopt-a-cop’ program in schools.

A community partnership between consumer and carer groups, the local mental health service and police provides a strong base on which all can be advocates on mental health issues and give support to each other. Together, all three parties can formulate possible solutions for difficult situations.

So, there is nothing stopping consumer and carer groups from contacting their local police station through the Senior Sergeant and initiating a partnership. Through this contact, police may also provide information on other activities that are already taking place, such as those described below.

A number of hospitals now have access to ‘Hospital Liaison Officers’. These are police officers with the role of linking the hospital with the police to address common issues and develop processes for situations which may occur. Their role is also to promote the police profile, providing education and support to those using hospital services. This is a good place for consumer and carer groups to become involved to give the police first-hand knowledge and valuable tips on the most appropriate ways to do their work in relation to mental health issues. The Hospital Liaison Officers are usually easy to access, as their role involves liaison with various groups to provide factual information on the culture of the police service and how best to establish links.

Some States and Territories (for example, Victoria) have developed protocols between the police service and the Psychiatric Services Division of the Health Department. Consumer and carer groups may want to get involved at this level, and should insist on being party to the development of such protocols.

Police officers receive their training in police academies. These academies may include components on mental health issues about the relevant Mental Health Acts and related topics. Some groups, for example ARAFMI in Brisbane, have developed links with police academies and provide lectures, seminars, and/or workshops to police cadets. The appropriate person to contact is the Police Academy Education Coordinator, or the equivalent.

Many branches of the police employ Community Liaison Officers who develop and maintain good links with the community and mental health services. Liaison Officers provide another ideal place to start when establishing relations with the police. If your local mental health service doesn’t have links with the local police service, the group may want to initiate such a partnership.

There are numerous links between the police and the general public. The police service can be an ideal advocate for mental health education and promotional work. A mental health consumer group located in a small town has made considerable impact by inviting local police to their educational and social events and through regularly mailing their newsletter to the police. This has resulted in good relationships and a more tolerant and respectful approach by police intervening in situations where people are experiencing symptoms of their illness.
Schools and educational institutions

When attempting to change community attitudes, young people can be excellent advocates. Students forming personal values and opinions within the education system are a receptive audience for health promotion. Often children will take ideas home and influence their families. Many schools play a pivotal role in promoting awareness of many issues including drug use, sex education and discrimination of all kinds.

Additionally, it is important for people to have an understanding of mental health issues from a young age, as many illnesses have their onset in late adolescence. Early recognition and prevention can considerably minimise the distress and severity of symptoms experienced.

However, mental health issues are not given a high profile in schools and educational facilities. Compared with the promotion of issues around sex education and drug education, the promotion of mental health issues is largely ignored within the school system. This is slowly changing, especially in relation to youth suicide.

Building a positive relationship

It is generally up to mental health community organisations to develop resources and take programs into schools to educate teachers, school counsellors and students. There have been some very effective mental health awareness workshops and programs presented through schools. One organisation, Mental Illness Education of Australia, has been particularly successful in this way. A number of community organisations have arranged for consumers and carers to speak with high school students to expose the myths and misunderstandings that surround mental illness, challenge stereotypes and give an accurate picture of the realities of mental illnesses and the people who experience them.

Key people to target for education and advocacy work include:

1. School counsellor/student welfare officer: often these are psychologists and the first person involved with students who may be experiencing problems at schools due to the onset of mental health problems.

2. School nurse: many schools, if they don’t have a counsellor, have a school nurse. The nurse is responsible for conducting health checks on students and can also end up providing support to students with mental health problems. School nurses rarely have any training in mental health and are often unsure how to help appropriately.

Workshops can be arranged by contacting the school or educational institution direct, or by creating links with education departments. Consumers and carers have identified a need to advocate for the inclusion of mental health issues in the curriculum of subjects that covers human issues, alongside environmental awareness, sex education and drug education.

Tertiary educational facilities also have limited information about mental illness and few resources for students. Many people who have mental health problems endure difficulties within the tertiary system and receive little or no support from academic staff or fellow students. Most facilities employ disability officers who can assist people having difficulties.
There are a number of creative methods that consumer groups can use to improve understanding within these environments. Student unions can be approached to support promotional activities ‘on campus’ during student orientation weeks, and to lobby for ongoing support of students with mental illness. University newspapers have a large student readership and are often receptive to articles relevant to their readers.

Student unions may assist mental health groups by lobbying for leniency for students experiencing symptoms of their illness during times of stress, whether study-related or personal.

Local government

When talking about ‘the community’, the authority that has most contact is the local council. The town or city council is responsible for providing local communities with the services they require. Councils are, of course, limited in what they can do, as they rely on income from the rates that the community pays and on grants from government. Consumer and carer groups often forget about the role that the council can play and the council, for its part, generally doesn’t encourage the community to be interactive. However, with mental health service provision involving the community more and more, councils need to play a larger role.

Raising the profile

In carrying out community development work, such as addressing the stigma and stereotyping that occurs in the community, the council needs to improve its involvement. Consumer and carer groups can develop a community partnership with the local council to address issues such as providing appropriate facilities within the community. A major cause of frustration reported by people with mental illness is the lack of community activities to keep them occupied during or after an episode of illness. The local council needs to assist the mental health community by providing recreational programs that encourage people with a mental illness to re-enter society and regain confidence after an emotionally shattering episode.

On discharge from hospital, ‘normal’ activities or work are generally not immediately resumed, and there are few activities available for a person recovering from an episode of mental illness. It is frequently reported by consumers that loneliness, boredom and depression can set in. Often a person re-enters hospital as a result of not having a worthwhile occupation.

One large city council has excellent programs for young and old people. Chill Out is a program for people under 15 years and GOLD (Growing Old and Living Dangerously) is for people over 50. Through these programs participants are offered a range of interesting activities such as abseiling, artwork, drawing classes, horse riding, jewellery making and dance. Despite the excellence of these programs, consumers report that there is little offered to people between the ages of 15 and 50, an age range the majority of people suffering mental illness fall into.
Local, State and Federal Government agencies

Training in mental health issues can be very beneficial to government departments and their employees. Officers who frequently deal with the public must become knowledgeable about dealing with people living with mental illnesses. Agencies such as Centrelink and employment and housing departments in particular need to be assisted through the provision of mental health education and raising awareness of varied symptoms of mental illness, from despondency to aggression. These services frequently deal with people living with mental illness in assisting them with disability support pensions, employment and training allowances and in finding suitable housing and employment.

Community groups

Service groups such as Apex, Lions Clubs and Rotary and religious groups such as St Vincent de Paul, Lifeline, Anglicare and Unicare carry out a range of humanitarian work. Funds raised by these groups in the community are often distributed to areas of need in the community. For example, specialised equipment is donated to people in need; vehicles are sponsored by Rotary and cash donations are made to worthwhile humanitarian organisations.

In promotional campaigns, community groups often give invaluable support by providing volunteers for mailouts, organising activities in their local area and promoting mental health issues. Groups such as Toastmasters have assisted campaigns by running speech competitions through schools and by donating time, resources and money.

Religious groups, such as St Vincent de Paul, Lifeline, Anglicare and Unicare, provide accommodation, counselling, emergency assistance, nursing services, food, flood and drought relief and a multitude of other services. Their activities are primarily funded through public fundraising appeals, opportunity shop sales and donations of goods.

Throughout the community there are neighbourhood centres that receive funding to assist members of the local community. Neighbourhood centres can give invaluable help to groups involved in advocacy, through providing a meeting place, photocopying and other supports. Neighbourhood centres also become involved in lobbying, advocacy and community development work. By developing a community partnership with these centres, consumer and carer groups can obtain a valuable ally.

Such community groups often request speakers to talk about mental health issues, providing good opportunities for consumers and carers involved in advocacy. They are also generally quite willing to display promotional material for mental health groups and many of their volunteers and staff are very keen to lend assistance.
Health professionals

Often the first port of call when a person suspects they may have a mental illness is the general practitioner. While some GPs are keenly aware of the symptoms of mental illness, too often they leave people with little help and even less hope. Up-to-date training of GPs by community mental health groups is essential. Groups can initiate this by contacting their local Division of General Practitioners. These Divisions provide training to GPs and many are interested in mental health, particularly from the consumer and carer perspective.

Medical practitioners are not the only professionals who have something to offer people with mental health problems. There are also psychologists, social workers, nurses, occupational therapists, naturopaths, homeopaths, nutritionists, to name just some of them. Consumers and carers have often reported that they obtain the best assistance from practitioners outside of the medical profession, yet can’t easily access them because they are not covered by Medicare.

There is much potential for advocacy in pushing for the opportunity to receive appropriate assistance from health professionals who demonstrate the ability to assist consumers and carers in the process of recovery from mental illness. Contact these professionals through their relevant professional associations, listed in the telephone directory.

Conclusion

There are numerous opportunities for developing partnerships with the broader community. The community is not just a target for advocacy, but also a potential ally in the battle to achieve equity for all community members.
At the heart of all advocacy activities undertaken by consumers and carers is an individual. This section of the Kit focuses on personal and interpersonal skills and strategies. They provide a firm foundation for self advocacy, peer advocacy and systems advocacy in conjunction with skills and strategies in other sections.

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Undertaking advocacy activity can be very rewarding, giving a sense of achievement and real empowerment. It can also carry with it some personal risk. It can be a gamble on fulfilment, success and disappointment. Putting yourself forward, being exposed to new situations, expressing your views is always challenging. Doing it in an environment of unequal power and stigma, like that associated with mental health issues, increases the challenge.

Consumers and carers who undertake advocacy activity talk, along with their stories of achievement, about the burden of responsibility, the stress of constant exposure, the sense of isolation and, inevitably, the need to look after themselves. Because if they fall over in some way, not only are they unable to continue the thread of their activity, but they lose credibility. The cynics will say, particularly of consumers, ‘His/her voice can’t be credible because he/she can’t take it’.

But win or lose, the process of advocacy, approached sensibly, will always make you a ‘winner’ because of its effectiveness in personal growth. Engaging in the process of advocacy will educate the cynics and provide you with invaluable learning for everyday life.

Even before you undertake advocacy activity, consider ways of preparing yourself. Advocacy activity requires effort. It also requires determination and commitment.

Your personal preparation is important. Do you have confidence that you will be able to help with the issue? Are you clear about how much you are prepared to do? Do you know how to maintain your own energy and interest? This section can assist you in working through these types of questions as you prepare for advocacy activity.

**Recognise that not all of your advocacy activity will succeed**

Overcome fear of failure by firstly acknowledging that you might be unsuccessful. Recognise that not succeeding, despite your best efforts, is okay and happens to everyone. Not succeeding is an opportunity to learn from the situation and to develop new skills, to know better what you are up against and to acquire further knowledge for next time.

Advocacy needs to include the knowledge that change will come in time. It may be useful to adopt an attitude of patience. Even if your advocacy activity cannot be directly measured as an immediate success, it is likely that the effort will contribute to change that is realised at a later time. Where you have been able to present a considered and reasonable position, it will help in breaking down the stigma and misconceptions held around mental illness. It will stand as part of a collective effort that eventually achieves broader systemic change. Remember though that some people will never consider your contribution to be reasonable.
Take stock of your knowledge, skills and resources

There are many ways of undertaking advocacy. There is a sufficient range of advocacy activities for everyone to contribute. Different activities require different personal attributes. Give some thought to your own personal attributes to make sure that you are striking a reasonable balance between extending yourself and stressing yourself. There is a Personal Stocktake worksheet on page 10 you can use to do this.

Identify in which areas your knowledge and skills can improve. Talk to others about ways for this to occur. Consider mentoring as one way of achieving this. (Also see: Maintaining personal effort in advocacy in the Knowledge and Attitudes Booklet.) Remember that one of your best resources is a trustworthy friend or associate who can support and advise you.

Learn to listen to yourself. Become aware of what you believe in and why, what you feel, the way you think. Listening to and understanding yourself will assist in getting your message across.

Take stock of your stress

Stress is a common human experience. At manageable levels it can be an important motivator to action. When our usual ways of coping are insufficient, stress may become a considerable burden. It can be harmful to you and to other people. It saps energy and creates distractions from other positive activities. The more you can know about what stresses you, how you react and how you cope, the more you can control it.

Try the Advocacy Fitness worksheet on page 16 as a way of gaining a greater understanding of your stress levels.

Increasing your awareness of what contributes to your stress will enable you to choose strategies that work for you. Consider some of the following:

- Have ways of distracting yourself. Read a book, draw, meditate, listen to music.
- Actively take a break. Walk around the block, pull up weeds, visit a friend.
- Pace yourself. Get in touch with your own rhythms. Know when you are usually not at your best and when your energy is at its lowest. Organise your activities and establish routines around your knowledge of your own capacities. Stop rushing.
- Focus on the task. Sort out what you are going to do and when you are going to do it. Put things in priority order. Keep reminding yourself of what you are doing and why.
- Value yourself. Think positive thoughts. Praise yourself for what you are doing. Look back and see how much you have achieved to reach this point. Take stock of your positive worth by writing down the good things about yourself and what you are doing. Use the Personal Stocktake worksheet on page 10. Stick a ‘what I like about me’ statement on your mirror and fridge door.
● Symptoms of physical and mental illness are often a first sign of stress. Acknowledge and accept responsibility for your symptoms. Do it early. Make them conscious and known to you by writing them down.

● Have some special support organised, for example, a therapist or a trusted friend, to help you through serious stress.

● Arrange for someone to tell you when you are exceeding your personal limits. Discuss with them your stress worksheet so that they can also assist you in recognising the signs of your stress.

● Organise opportunities for debriefing (see 2.1: Briefing and debriefing).

Create personal boundaries

Some advocacy activity is very demanding. You need to be honest with yourself about how much you are prepared to extend yourself. Decide what boundaries you are going to create for yourself before you commence. The Personal Advocacy Goals worksheet on page 13 can assist in this.

Take stock of your fear and anger

Fear and anger are always present in advocacy. Your feelings are not the problem but ignoring them can become one. Everyone experiences fear: of saying the wrong thing; of being inappropriate; of stuttering and stumbling; of making a fool of oneself. Strong feelings can be aroused by the injustice and inequity towards which advocacy is directed.

Recognising that these feelings are a common human experience is a good starting point to coming to terms with them. Everybody experiences these emotions. How much they show them is a matter of self-control. Getting in touch with your fear and anger can assist in overcoming them, in becoming less possessed and disempowered by them.

Fear

Managing fear in advocacy is mainly to do with self-appreciation and attention to goals. The more confident you are in yourself and what you are doing, the more you can achieve without your fears getting in the way. If your fears get in the way of you participating in advocacy activity, consider the following:

● You may not be afraid of the whole situation, only a part of it – focusing on what the fear is will make it easier to overcome.

● Plan and anticipate possible scenarios, assess the best and worst things that can happen and consider possible strategies for achieving best outcomes.

● Prepare well – gain as much information as possible and discuss the situation among your peers.

● Be clear on the good things about yourself and keep letting yourself know – use the Personal Stocktake worksheet on page 10.

● Undertake advocacy activities with which you feel comfortable – don’t be the spokesperson for something that you are not sincere and committed about.
- Be clear about the advocacy activity – name the purpose, set clear goals, plan what you are going to do.
- Find a trusted person to rehearse your strategy with.
- Be part of a larger organisation that can support your cause.
- Do it with someone else who has complementary skills.
- Start by being involved in advocacy at a level that is comfortable to you – observe how others participate successfully.

Anger
Like fear, the first thing to know about anger is that it is okay. It is a common human experience that has its benefits as a driving force to action. People seem to have two problems with anger that are not useful. One is to not express it, the other is to express it aggressively. Free expression of anger can get in the way of achieving advocacy goals. Getting angry at someone usually causes the other person to respond with equal passive or aggressive force. The result is that nobody wins.

Holding in anger, not expressing it, is a poor idea. Consider finding ways to acknowledge your anger. Verbalise your anger to yourself or write it down; tearing it up afterwards might also make you feel better. Collect people around you with whom you can talk through your anger. Make it clear to yourself that it is your reaction to a situation, not the fault of the other person. Avoid blaming the other person.

Try to remain rational about the situation. Consider whether your expectations of personal achievement in advocacy are rational. Are you angry because you haven’t achieved your goals in a situation where it has never been possible? Are you placing unrealistic expectations on other people? Maybe the circumstances are such that it is just too difficult to obtain a favourable response to your expectations. Seek to understand the beliefs, thoughts and feelings of others as well as your own.
Advocacy and the Individual

1.1 Looking after yourself

Be clear about what you are looking for. Sometimes anger can arise when you want the world to absolutely suit your own conditions. This emotion can go beyond frustration and lead to violation of the rights of others. When this happens you fail to take into account the rights of others in favour of your own ‘special’ rights. You can assist yourself to guard against this by:

- Tolerating your own frustration,
- Ceasing to be arrogant and self-important,
- Increasing awareness and acceptance of the rights of others,
- Becoming increasingly realistic about the world around you,
- Overcoming your own inadequacies,
- Becoming acquainted with the other person rather than assuming his/her motives,
- Recognising collective fallibility – knowing that everyone experiences disappointment at some stage,
- Not being consumed by the issue – moving on before consumption leads to bitterness,
- Maintaining a cooperative outlook,
- Remembering that the sought-after outcomes of advocacy activity can take a considerable time to achieve.

A large amount of advocacy activity involves direct communication with people who have the means to improve a situation. If anger is an issue at these times you need to consider:

- Being focused and clear about what you are striving for,
- Fully preparing yourself – focus, plan, organise and rehearse,
- Being consistent, authentic and genuine,
- Separating the issues from yourself, despite your passion,
- Learning to actively listen,
- Learning assertion over confrontation,
- Taking someone else with you whose role it is to support you in avoiding anger,
- Sticking to the facts – avoid dragging out imagined evidence in desperation.

Examine your own motives

Advocacy can be more rewarding when it achieves personal purpose. Sometimes it is possible to be clear about why you are doing something; at other times it is possible to be driven by a less clear passion to make something right. The clearer you are about your purpose, the more likely you are to succeed and to know that you have been successful, even if it appears that, overall, the activity has failed.

The fundamentals of advocacy are about addressing rights issues, injustice and inequity. Addressing these concerns is the aim of everyone who engages in advocacy activity at whatever level. Everyone’s motives, therefore, must be considered legitimate. Clarify your own advocacy goals. Use the Personal Advocacy Goals worksheet on page 13 to assist with this.
Sometimes personal motives can sit uncomfortably with group motives. If you are involved in group advocacy:

- Clarify the advocacy goals of the group with whom you are involved (the Personal Advocacy Goals worksheet on page 13 can be modified by a group for this purpose),
- Decide whether your goals are consistent with the group goals,
- Determine whether the group can effectively address your personal goals,
- Consider whether the long term advocacy goals of the group accommodate your own modified goals,
- Be clear that you are not taking advantage of a group of people to satisfy your own ends,
- Realise that the good of the ‘cause’ has higher priority than your personal goals.

Your motives for undertaking advocacy may go beyond the achievement of personal or group justice. They may include other legitimate and empowering motives like establishing a personal profile, gaining paid employment, learning new skills, gaining new knowledge. There is some risk in achieving these outcomes at the expense of others. Accomplishing these goals while not infringing the rights of others requires considerable care. A useful start to this is personal honesty. If you have used the Personal Advocacy Goals worksheet on page 13, you may want to review it.

Inevitably, some people will find personal opportunities in advocacy activity, such as training, employment, public speaking, writing. They risk accusations of being ‘not one of us anymore’ if their motives are not grounded in the fundamental purposes of advocacy. Maintenance of advocacy effort demands credible and sustained grounding in the consumer and carer ‘movements’, and continued honesty and affiliation to the cause. (Also see: The challenges of advocacy in the Knowledge and Attitudes Booklet).

**Take personal care**

All advocacy activity requires a level of personal commitment and effort. Much like preparing to play a sport, advocacy is improved by personal preparation and maintaining an adequate level of ‘fitness’.

The Advocacy Fitness worksheet on page 16 will help you determine a ‘fitness’ plan for yourself by giving attention to physical, social, emotional, intellectual and spiritual elements.

Personal appearance is important in influencing others. First impressions are particularly important, especially to those in more powerful positions. Remember, you want their image of consumers and carers to become more positive. Look good and you will feel good and, what is more, they will feel comfortable with you. If you want full participation take note of personal hygiene. Give consideration to the cleanliness and neatness of your clothing and general grooming. Tidiness does not have to be expensive. Feeling good about the way you look, in turn, increases self-confidence.

Organise your time to create balance between looking after yourself and your advocacy activities. Be mindful of the need to attend to the ordinary things like shopping, washing and ironing.
Adopting a stance or attitude about mutual respect is fundamental to getting what you want and to looking after yourself. The preferred outcome is both parties winning something from a situation.

Engaging in advocacy activity can enhance self-respect. Advocacy offers opportunities for learning and developing, gaining new skills and self-confidence, being affirmed by a peer group, achieving goals, creating an atmosphere of change and acceptance.

Self-respect is born out of treating others with the same dignity, consideration and patience that you would expect. It is a mutual process that reflects how successful you are in being attuned both to yourself and to others.

Identify your own barriers
Set realistic goals and expectations for yourself and others. This is part of caring for your wellbeing. The environment within which mental health advocacy is undertaken is, at times, hostile and uninviting. Remind yourself of the central challenges overviewed in the section on ‘The challenges of advocacy’ in the Knowledge and Attitudes Booklet.

Sometimes people create their own barriers. They create difficulties for themselves in their attitudes and their fears. Consider the relevance of the following statements from consumers of mental health services in Canada (CMHA) and Australia:
‘Feeling we have nothing to contribute because we do not see our own value’
‘Being frightened of authority or putting such people on a pedestal’
‘Becoming very dependent on others and feeling sick and helpless’
‘Not knowing about our rights or not daring to get our rights’
‘Becoming less concerned about what goes on in the world’
‘Becoming isolated and feeling lonely’
‘Not knowing what it’s like for others to show us respect’
‘Being really tough on ourselves and afraid of failing’
‘Being afraid of our anger or letting it take over’
‘Accepting negative attention rather than no attention at all’
‘Blaming one’s illness and/or medication’
‘Feeling we don’t have the right words to express ourselves instead of using simple words’

Here is space for you to add in some personal statements.

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Lack of knowledge and skills and lack of self-awareness can be personal barriers to effective advocacy. Use some of the worksheets at the end of this section to identify your strengths and areas for improvement.

Self-confidence and fear of exposure are sometimes more problematic than lack of knowledge and skills. Self advocacy involves identifying who you are as a person and openly acknowledging the way others see you, including both the value they place on you and the impersonal and disempowering stigmatising and labelling. Adopt an attitude about the way you present yourself. If open exposure is hazardous, engage in supportive advocacy activity within an organisation rather than being a ‘front person’.

Develop ways to gain support

Friendships bring opportunities to share ideas; rehearse presentations; feel part of a collective view; gain mentorship and affirmation; find an appropriate role; give and receive debriefing.

Support is about not being alone and being able to share in a safe and comfortable setting. Finding support requires reaching out and exploring. Personal support can come from almost anyone and unusual sources should not be overlooked. Sometimes support is about talking through some issues; sometimes it is about being in the right environment that enables you to feel good about yourself. You might want to include friends and relatives, therapists, support workers, even your pets. Be with them where it is comfortable for you.

Consider more formally the types of support you need, who will provide it and how it is going to happen. Some forms of support, like debriefing or consultation, need to be organised and negotiated. It is empowering to ‘use’ support rather than to passively receive it. Be careful to ensure that support is by mutual agreement rather than burdening others. Accept support under the same conditions that you would expect to give it yourself. (Also see 2.1: Briefing and debriefing.)

Use support as a way to empowerment. Try not to put yourself in the position of needing to be ‘rescued’, that is, letting others do things for you that you are capable of; letting people assume they know what you want; having people assume you can’t handle something that you can; having them do something for you that they really don’t want to do.

Avoid burn-out (lack of energy and enthusiasm, anger and frustration, a sense of futility, lack of goals) by maintaining your role and purpose; setting limits on your time and work; having your contribution recognised; stopping people being dependent on you; discussing the issues; recognising your own limits and establishing mutually rewarding relationships.
Advocacy and the Individual

1.1 Looking after yourself

Self-promotion

It is quite legitimate to demonstrate your strengths and talents in advocacy and to have them acknowledged. Consumer and carer movements need leaders who have respect from their peers and credibility with a broader audience. Such recognition comes from:

- Dedication and sustained interest,
- Achievement,
- Working hard and working smart,
- Knowledge of the issues,
- Demonstration of thoughtful planning and delivery of advocacy activity,
- Being in the right place at the right time,
- Writing for publication.

The danger of self-promotion in advocacy is the loss of connectedness to the people and events that provoked your action in the first place. Enjoying self-gain at the expense of those who have contributed to your advancement is usually considered unacceptable. Consider how you can use your gains to assist others, to lead by example and to remain true to the fundamentals of advocacy.

There may be occasions when you want to engage in some formal self-promotion – seeking employment, public speaking, applying for higher education courses, formal representation. An important part of this is taking stock of your relevant attributes and experiences.

On page 24 there is a Personal Resume worksheet that enables you to create your personal advocacy resume.

References

Canadian Mental Health Association (1994) Board and Committee Survival Handbook for Consumers of Mental Health Services, Kelowna, British Columbia
Leader A Direct Power: A Resource Pack for People Who Want to Develop Their Care Plan and Support Networks, MIND, London
National Depressive and Manic Depressive Association (DMDA) Leadership Handbook, Chicago
Spaniol L, Koehler M, Hutchinson D (1994) The Recovery Workbook: Practical Coping and Empowerment Strategies for People with Psychiatric Disability, Center for Psychiatric Rehabilitation, Sargent College of Allied Health Professionals, Boston University
Personal Stocktake

Use this worksheet periodically; say, once a year or before a major advocacy activity comes up. Keep in touch with where you are at in relation to your capacity to undertake advocacy activity. Use it as a planning tool to decide how you can put your talents to good use and how you can develop in areas that might be beneficial.

Copy these and stick them on your mirror and the fridge

<table>
<thead>
<tr>
<th>What do I really like about myself?</th>
<th>(for example, good listener, well organised, nice hair)</th>
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<th>What are my personal weaknesses?</th>
<th>List those areas where you wish you had more confidence (for example, I can’t say no to people wanting my time)</th>
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<th>What do I know that will make a useful contribution?</th>
<th>List particular knowledge from your experience or interests (for example, I know how to find things in a library)</th>
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### What skills do I have that may be useful?
List the particular things that you can do quite well (for example, write good letters)

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### What do I enjoy?
List those things that are satisfying to you that may show you a good starting point for advocacy (for example, talking in groups of people)

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### What don’t I enjoy?
List those things that invoke some fear or panic (for example, talking to people on my own)

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### How can I learn and improve on my knowledge and skills?
List some options (for example, join an organisation, get involved in a particular advocacy activity)

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### In what things do I need support?

List the most important things (for example, before I attend a meeting with service providers, help to read reports)

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<tr>
<th>Support Needed 1</th>
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<tbody>
<tr>
<td>Help to read reports</td>
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<tr>
<td>Assistance with transportation</td>
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<tr>
<td>Preparation for meetings</td>
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<tr>
<td>Emotional support</td>
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<td>Planning for future activities</td>
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1.1 Looking after yourself
### Personal Advocacy Goals

Use this worksheet to begin to plan your advocacy activity. It can be used in conjunction with the Personal Stocktake worksheet or on its own to sort out your personal advocacy goals. State them clearly, work out the resources available to you and make sure the two merge together.

#### Where has my desire to undertake advocacy activity come from?
Make some notes as a reminder of why you are doing it (for example, because of what happened to me when I was admitted to hospital)

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#### What do I want to achieve through advocacy?
List the most important rights issues, injustices, inequities of concern to you (for example, increased respect by service providers)

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#### What personal barriers do I put in the way?
(for example, I always say, ‘I can’t do it’, when I know with support that I can)

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1.1 Looking after yourself

What boundaries am I going to set on personal disclosure?
List the conditions under which you may or may not be fully open about your background (for example, I am not prepared to discuss my personal abuse background in an open forum)

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Having taken stock of my personal attributes, my advocacy goals, the organisational/group supports available to me, are my goals achievable? If not, break them down into smaller goals that can be achieved and that will contribute to achieving your main goals. List these as your new goals.
Advocacy Fitness worksheet

Use this worksheet to improve your understanding of what assists you in maintaining advocacy effort. Work through some strategies for physical, social, emotional, intellectual and spiritual wellbeing. Get in touch with what stresses you and how to recognise early signs. The strategies are endless but may not be easy to identify. Talk with some other people about the methods they use.

Physical
What do I know about my physical self that reduces my capacity for advocacy?

<table>
<thead>
<tr>
<th>Physical fitness</th>
<th>(for example, I know that my current inactivity makes me easily tired)</th>
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<table>
<thead>
<tr>
<th>Rest and relaxation</th>
<th>(for example, if I don’t get enough sleep I get irritated, sometimes I just need a break)</th>
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<table>
<thead>
<tr>
<th>Diet and nutrition</th>
<th>(for example, sometimes too much coffee makes me ‘nervy’)</th>
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What am I going to do to try to assist these things?

**Physical fitness**  
(for example, I will go for a 15 minute walk every evening)

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**Rest and relaxation**  
(for example, I will try not to sleep during the day, I will carry a book around with me to read when I want to)

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**Diet and nutrition**  
(for example, I will only have five cups of coffee a day)

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### Social

#### 1.1 Looking after yourself

<table>
<thead>
<tr>
<th>What do I enjoy about my social life?</th>
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<tbody>
<tr>
<td>(for example, regular outings with my closest friends)</td>
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<table>
<thead>
<tr>
<th>What do I need to do to improve my social life?</th>
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<tbody>
<tr>
<td>(for example, make stronger commitments to people)</td>
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1.1 Looking after yourself

What do I know about where the feelings come from? What sets them off? (for example, I get afraid that I won’t know enough when a group of people are talking together, I don’t like change that affects me)

What are the good feelings that are most prominent when I think about advocacy activity? (for example, connectedness, achievement)

What are the stressful feelings that are most prominent when I think about advocacy activity? (for example, fear and anxiety)

What do I know about where the feelings come from? What sets them off? (for example, I get afraid that I won’t know enough when a group of people are talking together, I don’t like change that affects me)
How do I usually react when something is stressful?
Think of the physical signs (for example, I get a dry mouth),
the action signs (for example, I want to get out of the room)
and the emotional signs (for example, I feel embarrassed)

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What do I usually do to deal with my stress?

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Do these strategies always work? If not, what is the problem with them?

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What more useful and productive ways are there to deal with the stress?

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### Intellectual

**What do I do to challenge myself? List the ways that you keep mentally alert.**
*(for example, read, do crosswords, help other people solve problems)*

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Spiritual

What overall purpose do I see in advocacy? Does it make sense to me? Does it fit comfortably with other beliefs, thoughts and feelings I have about the world around me?

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What activities will I consider for focusing myself? (for example, self-reflection, starting or joining a discussion group)

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Personal resume

Create your own style for your personal resume. Whether it is typed (preferred by most people) or neatly handwritten, this worksheet can be used as a guide to the sorts of things to include. Usually, most of this information is required for work applications. A summary version may be sufficient for other engagements.

Name: Jane Smith
Address: 7/42 Cardigan Place
         Mt Isa QLD 4825
Date of Birth: 11/8/62
Telephone: 07 3712 3456
Qualifications: (List educational qualifications)
  Example:
  Certificate in Office Administration
Referees: (Names and contact details of people who have agreed to provide either employment or personal comment about you in support of your application)
  Colin Friend
  Manager
  Lock, Stock and Barrel Apparel
  07 3712 4567

Employment History:
(Where you have undertaken work, you should list your positions in date order, showing the most recent one first. Include unpaid work. If your employment history has been severely affected by periods of illness, you need to decide how to manage this. Talk to other consumers about their experiences before committing yourself.)

August 1994 - April 1998
Sales Assistant
Lock, Stock and Barrel Apparel

In this position I was responsible for meeting customer purchase needs, maintaining sales records and keeping track of stock requirements, etc.

I was sometimes the sole person in charge of the shop and was responsible for accounting for the takings at the end of the day, etc.
Personal Attributes:
(You may not have an employment history or you may not be using your resume for seeking work. Even if you are, listing your personal attributes is a good way of affirming yourself and raising self-confidence. Write down those things that you have experienced, achieved and where you have particular knowledge or skills that demonstrate your worth. You can use the bits that appear relevant to the particular job/engagement you are considering.)

As a consumer of psychiatric services, I have a well developed interest in the dominance of masculine interests in traditional psychiatric rehabilitation services, etc.

As a parent of a person with mental illness, I have experience in some of the ways that mental health services operate, etc.

During my two years as a member of the youth club committee, I developed skills in committee work, report writing, etc.

Courses Undertaken:
(You may have done some training or development of relevance.)

In September 1995, I undertook a series of evening classes in assertiveness, etc.

Papers:
(Perhaps you have had an article published, presented something at a conference or seminar or received credit for writing something that had influence.)

In February 1996, I wrote a short paper on improving consumer participation. It formed the basis of discussion from which the Day Centre created a consumer participation policy. My effort was acknowledged in the policy document.

Summary:
A summary statement of yourself can be useful, to send to someone who is looking for a representative, or to introduce you before giving a presentation. Each summary statement will look a little different depending on its purpose. Using this worksheet will assist in listing all the things from which you can choose to go into your summary. It will also assist you in creating an appropriate covering letter for your job application.
1.2 Remembering who you are

‘I’ve learnt another language but sometimes I feel like I’ve lost my native tongue.’

Simon Champ commenting on working with bureaucrats

A lot of the material in this Kit is about how to do things: it is about speaking and writing; about sitting on committees and conducting ethical research; about educating others and about self-education. All of this is important, but some consumers and carers who have been politically active for a long time feel that, while they have gained a great deal of ‘professional’ expertise and ability, they have also lost something of themselves along the way.

Other sections in this Kit talk about consumer perspective and carer perspective. How do you keep your perspective over time? How do you stay in touch with the feelings and experiences of other consumers and carers?

‘Consumer perspective is about … having a profound respect for each other, and a deep recognition of the legitimacy of other consumers’ feelings, views, beliefs, ideas, opinions, attitudes and ways of living. … When we are really using a consumer perspective we have pride, not shame. … It’s also about being dissatisfied with situations we experience as hurtful, and (about being) committed to changing them. Because we aim not to disempower each other, we aim to consult each other and work together rather than ‘going it alone’ and risking imposing our solutions on each other … most of all we try and keep going, to improve things for all of us.’

Wadsworth and Epstein, 1966

Talking from your own knowledge

Put simply this means talking about what you know. If you talk about things that you have experienced you are coming from an ‘expert’ position. (Also see 3.9: Being the ‘layperson’ among ‘experts’.)

Knowledge, in this case, does not mean book-learning, or how many degrees you hold. It means your knowledge and experience of what it is to be a consumer or carer (or possibly both).
A fundamental issue around talking from your own knowledge is that you respect other consumers and carers who are talking from their own knowledge. You must remember how to listen as well as knowing how to talk. Keeping your consumer (or carer) perspective healthy involves listening to the stories of others who may lack your political awareness. Be careful to listen well.

**Finding your own style**

Finding your own style, what works for you and feels comfortable, is often a matter of trial and error. Remember that what works for one person does not work for everyone. Here again there is a need to retain and nourish consumer (or carer) perspective. While you may have to negotiate or even do battle with the system in pursuit of rights, try not to be drawn into playing by a set of rules that devalues that perspective.

- Do not feel obliged to cite learned authors or rattle off statistics if that is not your thing.
- While it is often helpful to get advice from people whose opinions you trust and respect, do not let yourself be coerced into adopting a style which does not feel right for you.

**Consumer/carer perspective and individual advocacy**

In many advocacy situations you can assist or, occasionally, act on behalf of another person or persons. Even self advocacy usually has repercussions for others in similar situations. Before taking any action, think carefully about the implications and consequences for other consumers/carers: that is, have a consumer (or carer) perspective.

An advocate is often required to assist another person in putting forward views to people in a more powerful position. The advocate needs to make sure that he/she is accurately expressing the person’s views and wishes rather than superimposing his/her own views about what is best for that individual.

‘If you do not feel a thing, you will never guess its meaning.’

Emma Goldman

A good advocate will take time to get to know the person they are to assist. This includes offering practical help, listening to what the person has to say and encouraging the person to express his or her wishes about treatment, housing or whatever the issue might be. Often, in this individual advocacy situation, the advocate is there for moral support rather than as a mouthpiece. However, there are occasions when a person may find themselves having to actually speak on behalf of another.
There may be straightforward situations in which you are essentially a messenger delivering someone else’s message. Perhaps the person you are representing lacks confidence or has some other reason for preferring to speak through another. In such situations you need to make sure that you can and do **pass on the message accurately and to the best of your ability.** (Also see 3.2: Telling stories: Using other people’s stories.)

If at all possible, make sure you **do not assume** that you know what another person thinks, wants or needs – ask them.

More difficult are the situations in which a person cannot (for whatever reason) tell you what to say on their behalf. There is no single or easy solution to this one.

Sometimes it may be possible to discuss what the other person would want to happen if a certain situation arose and they were unable to represent themselves. In this case you would have a responsibility to carry out the person’s wishes or to see that they were carried out. (Also see 1.9: Creating a personal advocacy plan.)

Prior arrangements such as this are not always in place or possible to put in place. If you find yourself in a position of being an advocate for someone who cannot express their wishes or whose expressed wishes are unarguably against their own interests, then you must be prepared to **put the needs of that person first, before your own.** Seek advice and support from friends and from organised consumer/carer groups. If you feel you are too close to the situation to act objectively, you need to step aside and allow someone less involved to participate.

Whether you are a consumer or a carer or both, and however you choose to participate, try to remind yourself every so often just why you became involved in the first place. Nurture and renew your connections with other consumers and carers. **If the consumer and carer movements are to continue to bring about change, then the individuals and groups making up those movements need to remember who they are.**

References

1.3 Assertiveness

Assertiveness is viewed as the open and appropriate expression of thoughts and feelings, with due regard to the rights of others. Being assertive means understanding your rights and sticking up for them without being aggressive.

Have you ever:

- Hesitated to question a mistake on a restaurant bill because you were afraid of making a scene?
- Backed out of telling a shopkeeper that he short-changed you because there were a lot of people in the shop waiting to be served?
- Said ‘yes’ when you wanted to say ‘no’?

Do you have trouble being assertive? - You’re not alone

A term which is well known, especially to consumers, is compliance. Complying with requests is a normal part of daily social life. But there are some times when a willingness to comply can exceed what is reasonable. A researcher by the name of Thomas Moriarty became interested in the personal insults, rebuffs and sacrifices of dignity that are common in life. Moriarty observed that many people are non-assertive to the point where they put up with almost anything to avoid a confrontation. He decided to put this non-assertive, non-hassle attitude to the test.

In one experiment, two subjects (one an accomplice of Moriarty’s) were given a difficult test in a small room. As soon as Moriarty left the room the phoney subject turned on a portable cassette player at full volume, giving the other person a 17 minute blast of rock music. Incredibly, 80 percent of subjects said nothing, although they glared, cupped their ears, stopped work and so forth. At later interviews the subjects indicated they were angry or annoyed but were afraid to tell the other person to be quiet (Moriarty, 1975).

To show that this non-assertive nature of people also exists outside of the controlled experiment setting, Moriarty and his students staged loud conversations behind theatre patrons and people studying in a library. Very few people protested. In another setting, people in telephone boxes were confronted and asked if they had found a ring that had been left in there. When they replied that they hadn’t, they were demanded to empty their pockets. Most people emptied their pockets.

In these and similar situations, people passively accepted having their personal rights trampled, even when objecting presented no threat to their safety.
Most of us have been rewarded, first as children and later as adults, for compliant, obedient, or ‘good’ behaviour. Perhaps this is why so many people find it difficult to assert themselves. Or perhaps non-assertion is related to the anxiety that accompanies ‘making a scene’ or feeling disliked by others.

Every human being has three basic rights:
The right to refuse,
The right to request,
The right to right a wrong.
Self-assertion involves standing up for these rights by speaking out on your own behalf. Self-assertiveness is not just about getting things your own way. A basic distinction can be made between self-assertiveness and aggressive behaviour. Assertiveness is a direct, honest expression of feelings and desires. It is not exclusively self-serving, since pent-up anger can be very destructive to relationships. People who are non-assertive are usually patient to a fault. In contrast, aggression does not take into account the feelings or rights of others. Aggression is an attempt to get one’s own way, no matter what.

Comparison of Assertive, Aggressive and Non-assertive behaviour

<table>
<thead>
<tr>
<th></th>
<th>Initiator</th>
<th>Receiver of behaviour</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Non-assertive behaviour</strong></td>
<td>Self-denying, inhibited, hurt and anxious; lets others make choices; goals not achieved</td>
<td>Feels sympathy, guilt or contempt for initiator; achieves goals at initiator’s expense</td>
</tr>
<tr>
<td><strong>Aggressive behaviour</strong></td>
<td>Achieves goals at others’ expense; expresses feelings but hurts others; chooses on behalf of others or puts them down</td>
<td>Feels hurt, defensive, humiliated or taken advantage of; does not meet own needs</td>
</tr>
<tr>
<td><strong>Assertive behaviour</strong></td>
<td>Self-enhancing; acts in own best interest; expresses feelings; respects rights of others; goals usually achieved; self-respect maintained</td>
<td>Needs respected and feelings expressed; may achieve goal; self-worth maintained</td>
</tr>
</tbody>
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Adapted from Alberti and Emmons, 1978
How to become more assertive – self-assertion techniques

Everybody can learn to become more assertive by practising each assertive action until it can be repeated even under stress. For example, imagine the following scene: you’re waiting to be served at the local take-away café where you’re buying lunch and people who arrive after you are being served before you; you’re due back at work soon and won’t have time to eat what you’re trying to buy; you’re getting a little upset and perhaps a bit angry.

To improve your assertiveness in this situation, you can begin by rehearsing the dialogue, posture and gestures you can use to confront the shop attendant another time. Working in front of a mirror can be very helpful or, even better, role-play the scene with a friend. Have the friend take the part of a really aggressive shop attendant as well as a cooperative and pleasant one.

Rehearsal and role-playing can also be used in any situation where you expect that there may be some confrontation, for example, when you’re discussing the oven that won’t work with your landlord, or when you’re discussing some unacceptable treatment that you received in hospital with the senior nurse or doctor.

Another important principle in working at becoming more assertive is ‘overlearning’. When you rehearse or role-play assertive behaviour, it is essential to keep practising until your responses become almost automatic, otherwise you will probably become flustered in the actual situation.
Another technique which can be very useful is the ‘broken record’. A useful way to stop assertion becoming aggression is to simply restate your request as many times and in as many ways as necessary. In the box below is an illustration of how the ‘broken record’ can be used:

**The manager can’t see you now**

**Individual:** I would like to see the manager about the abuse that I received from two of his staff.

**Manager’s Assistant:** I’m sorry, but without an appointment you can’t see the manager.

**Individual:** I have just been abused by two staff members and I would like to speak to the manager now as the matter is extremely serious.

**Manager’s Assistant:** There is an appointment available Friday morning next week if you would like to see the manager then.

**Individual:** I understand that I don’t have an appointment, however, as the matter is very serious I would like to see him now.

**Manager’s Assistant:** The manager is a very busy man and can’t just see people when they want him to.

**Individual:** I’m sure that the manager is busy, however as the matter is very serious, I would like to see him now.

The individual asking to see the manager hasn’t become aggressive with the assistant, hasn’t quit, nor passively gone away. Quite often, simple persistence is all that is necessary for simple self-assertion.
Sometimes people may be plainly rude or aggressive. Generally people strongly feel the urge to retaliate in a similar fashion. But, if this happens, the outcome is unlikely to be very favourable for them and all that occurs is an escalation of angry emotions. Responding assertively in these situations is a real challenge. An assertive way to respond verbally to aggressive people is:

1. If you are wrong, admit it,
2. Acknowledge the person’s feelings,
3. Assert yourself about the other person’s aggression,
4. Quickly end the conversation.

Below is an illustration of how to use these four steps:

You have just come out of an important meeting when a member of your advocacy group comes up to you and says angrily, ‘You absolute idiot; what a stupid thing you said in there. Why don’t you use your brain. You’ve probably stuffed everything up for all of us’.

An assertive response, using the four steps outlined above, is: ‘I’m sorry if I said the wrong thing. I didn’t do it intentionally. It’s obvious you’re upset, but I don’t like you calling me names or yelling at me. I can understand your point without that’.

Learning self-assertion skills may be difficult at first. However, with practice and use, they can become easier and eventually can be mastered.

In summary, self-assertion is not necessarily confidence or self-assurance. It is a way of combating anxieties associated with living in an often impersonal and competitive world. Self-assertion is empowering in that it maintains the right to refuse, the right to request and the right to correct a wrong.

There are a great number of good books and articles written on self-assertion which the reader may be interested in following up. These are often available from various libraries. A number of organisations also run courses on self-assertion, often at little cost to the participant.

References
Alberti R & Emmons M (1978) Your Perfect Right, Impact, San Luis Obispo, California
One thing people can be sure about: there will always be problems. Whether they are large or small, problems are part of life. While people generally like to believe that they want to live in a problem-free world, when they really think about it, life might be pretty boring. Generally, people actually like to solve problems. If people don’t find ways to overcome problems they don’t enjoy success. The problems people really want to be rid of are the ones they can’t solve.

While individuals enjoy the rewards that produce success, they also enjoy the process that produces success. **People will accept, and may even seek out, problem-solving opportunities if the following four conditions are met:**

- They must possess the skills needed to solve the problems that arise,
- They must experience success in using those skills,
- They must be rewarded for successfully resolving their problems,
- They must not fear failure.

The opposite of this is equally true. **People will avoid problem-solving situations when:**

- They are unsure how to solve their problems,
- They do not experience success after trying to solve a problem,
- They feel their efforts are not appreciated,
- They sense they have less to lose either by doing nothing or by shifting responsibility.
Types of problems

People encounter all sorts of problems, both technical and non-technical, which need solving. Two main types of problems are close-ended and open-ended.

Close-ended problems

Close-ended problems are those which have single correct solutions or sets of solutions. Often the solution doesn’t need to be tested. For example, you walk into the room where you are attending a meeting and the light won’t come on. You can quickly narrow the problem down to a small number of solutions:
1. The light bulb has blown,
2. The fuse has blown,
3. The power has been cut off.

By seeing that the rest of the lights are on you quickly find out the bulb has blown. The following questions may help you determine if a problem is close-ended:
● How much is known about the problem?
● Is complete and adequate information known?
● Do procedural methods already exist for solving the problem?

The more questions that you have answered with ‘yes’, the more likely you are faced with a close-ended problem. These problems are not usually difficult to solve. In fact, individuals can usually handle close-ended problems themselves, without calling for the problem-solving capabilities of others. Unfortunately open-ended problems are a different matter.

Open-ended problems

Open-ended problems do not have simple solutions because, unlike close-ended problems, you don’t have the information to solve the problem readily at hand, or else the information is not readily understood. These sorts of problems are often a whole range of problems which manifest themselves as one problem. Like a jigsaw puzzle, there are interconnecting pieces which must be viewed separately. For example, how do you change the culture of an organisation? Each part of the culture is a piece of the puzzle. Taking it apart and changing it creates a new picture. There is no ‘correct’ answer.

The only ‘correct’ answer to an open-ended problem is the answer that works best.

Groups are best suited to ‘solving’ open-ended problems. Groups bring information and experience to problems and, through ‘brainstorming’ together, can come up with workable solutions. As a team, the group needs to process and filter information to test, refine and finally select the best solution. The real criterion for the correctness of the solution is the group’s acceptance of the decision as correct.
1.4 Problem solving

**Cause and effect**

Problem solving requires cause-and-effect thinking. A problem is the visible effect of a cause that has occurred in the past. The effect observed needs to be related to its exact cause. Only then is it possible to be sure of taking the appropriate corrective action – action that can correct the problem and keep it from recurring. This is often the most difficult part of problem solving, and the part that most people spend the least amount of time on, while on the look-out for a quick and inexpensive solution. Unfortunately, time and resources are often wasted on wrong solutions before the right solution is hit upon.

Problems can also be categorised as new problems or pre-existing problems. That is, problems which develop when they never existed before (for example, the group has always been requested to run workshops at the university, but recently these requests have stopped), and problems which have always existed to some extent (for example, the group has never been able to access the university to run workshops). Both types of problems can be approached through techniques of problem solving using the following steps:

- Definition of the problem,
- Description of the problem,
- Generation of possible causes,
- Testing for probable cause,
- Verification of true cause.

To apply these steps, take the example of a group which has been very successful in providing education workshops in a range of settings, such as universities, the police academy and several newspaper companies. In the last six months, the group has not received any requests from a number of departments within a university, despite the group having sent the usual information package to the university at the start of the year.

**Define the problem**

‘Decline in the number of workshops requested by all three departments at the University of Doubt’.

**Description of the problem**

One of the major objectives of the group is to be involved in the development and delivery of courses to students enrolled in courses for mental health professionals. This has become quite successful, although in the last six months three departments in the University of Doubt have not requested the group’s involvement in any way. This is causing a lot of concern.
Generation of possible causes
The group lists a range of possible causes:
1. The workshops have lost the flair they once had,
2. Course coordinators have decided the students don’t need the kind of information that the group provides,
3. Students have lobbied the course coordinators to drop the workshops,
4. The university itself has made a decision not to involve consumers and carers in any of its courses,
5. The university’s departments didn’t receive the information package mailed out to them, including details of the group’s new address and phone number.

Testing for probable cause
The group goes through each one of the above possible causes:
1. The members decide that, as the workshops were continually modified to keep them ‘exciting and effective’, and as feedback from other universities and organisations is very positive, the first possible cause is not probable.
2. As the group provides workshops to three different departments within the university, it is unlikely that all three coordinators have decided that their students didn’t need the kind of information provided by the group.
3. The members believe that students always found the workshops to be very beneficial and this is reflected in the evaluation sheets completed by the students following every workshop. As for the second cause, it is unlikely that students from all three departments are suddenly dissatisfied.
4. The group feels that it is possible that the university has made a policy decision across all departments not to involve ‘non-professionals’ in the teaching of students. However, the members feel sure that as they have good relations with the individual course coordinators, the group would have been contacted if this were the case.
5. The group moved to a new location about seven months ago and now has new telephone and fax numbers. Everyone on the mailing list has been provided with the new details and the group is not aware of any problems. However, the group agrees that if the university did not receive these details, it explains why all three departments have not contacted them.
Verification of true cause

The group decides first to check the mailing list to ensure the university’s departments are listed. They are not. When the group discusses this, one of the members recalls that there was a problem with the computer when they moved and a new mailing list had to be constructed. As it turns out, the mailing list was constructed from an old list which did not contain any details of the university’s departments.

The group decides to verify this probable cause and rings the three departments and finds out that they did not receive the information package. Later conversations with the three course coordinators reveals that they have been concerned that the group had run into difficulties and ceased operation. They are relieved to hear that the group is still in a position to run the workshops.

The workshops are resumed and the mailing list checked to ensure it is accurate and up-to-date. The group also develops a procedure to ensure the mailing list is always kept accurate to avert any future problems.

Although this is a relatively easy problem to solve, the steps for problem solving are the same, no matter how easy or complex the problem. By solving relatively simple problems, individuals and members of groups can gain confidence and perhaps even enjoy the challenge of tackling complex problems.

Sometimes it has to be accepted that the problem is just too difficult, is consuming too much of the group’s energy, and it may be a good idea to get another person to shed ‘new light’ on the problem. However, as pointed out earlier, there are problems for which there are no solutions and, unfortunately, that’s life.
Personal administration and organisation

Personal administration and organisational skills can be of great benefit, not only in conducting advocacy, but across a range of settings. If individuals have poor skills in these areas, they tend to spend a lot of time completing tasks, leaving less time to do other, more enjoyable things. Some people can spend too much time on administration, to the detriment of the work they are doing. Others spend too little time on administration, until it catches up with them and there’s a great panic. Perhaps the best example of this is taxation return time – people soon realise how fast a year goes when it’s time to get the tax return in.

Developing a personal plan

One way to be efficient in personal administration and organisation is to plan to be that way. A personal plan may sound very grand, but it can actually be very simple. Below are some ideas to help with developing such a plan.

1. Decide how much time you have available for work activities
   In deciding how much time you have available for work, take into consideration the time you need for other things like ‘having a life’, spending time with family and friends, and having time to yourself. Take into account travelling time, and time involved reading and writing material and doing paperwork. Advocacy work can be very stressful (as well as very rewarding), so it’s better to initially commit yourself to undertake less work than you think you can actually handle. You can always increase your workload if you find time on your hands, but it can be difficult to cut back on work once you have said that you can do it.

2. Decide the amount of time needed for tasks in relation to the number of tasks you are undertaking
   Before you commit yourself to undertaking a number of tasks, work out roughly how much time each can take. Maybe you can only undertake one task if it uses up the overall time you have allotted to work. It’s easy to fall into the trap of agreeing to do a number of tasks which seem relatively easy, only to find that you haven’t got time for any others. It’s a good idea to add an extra 20 per cent on top of the time you estimate, just for the unexpected.

3. Make a priority list of the work that has to be done
   This list can be prioritised from urgent to less urgent. Put the list up on the wall in a prominent position so that you can see it. As you complete tasks, cross them off the list. If the list is continually growing, that is, the rate of setting tasks is greater than the rate of completing tasks, then you need to either spend less time on specific tasks or reduce the number you are doing.
4. Decide on a place to work from

Unless you are lucky enough to have an office, you will need to find somewhere to do your work. It’s good if you can find one place which is yours and yours alone; it may only be one corner of a room, but it’s your space. Find a place to put the things that you need for your work, and keep these things in their place. Filing cabinets are great, but cardboard boxes work almost as well.

It can also be helpful to make monthly and weekly plans. A monthly plan might consist of a list of activities you anticipate completing in the coming month. These activities need to include all those such as attending meetings, conducting workshops, reading paperwork, attending courses and workshops and completing administration work. When preparing this list, be specific and name the actual activities.

A weekly plan might mean you sit down on a Sunday night or Monday morning and make a list of the tasks and activities you need to complete that week to ensure you’re on track with your monthly plan. Again, be specific.

Everything in its place and a place for everything

... so the old saying goes. Being organised has a lot to do with being tidy with paperwork and work material. Being tidy begins with having somewhere to put things where they can easily be found again. When something is finished with, it needs to be put back in its spot at that time. This way things never get untidy in the first place.

Having an untidy workplace where nothing can ever be found can be stressful and can make a person feel out of control. Of course, everyone is different, and some people find that they feel more comfortable with lots of ‘stuff’ lying around. If you are like this, or if you find that you can’t get into the tidiness habit and have books, papers, pens, and computer disks lying around all over the place, a good strategy is to have a clean-up at the end of each week. This stops things from getting out of hand.

Get into the habit of ‘not putting off work’

Easy to say, but harder to do. Look at it this way – those tedious, boring administration jobs are not going to go away. The more you put them off the more they mount up and the more you will want to put them off. Attend to administration tasks every day and keep them manageable.

Managing paperwork

One thing that often confronts consumers and carers who become involved in advocacy and community development is the vast amount of paperwork to read and comment on. Sometimes people suspect that this is a deliberate ploy to keep them busy so they don’t have time to focus on ‘causing trouble’. Many people find it difficult to get into the habit of setting aside specific time for paperwork. Even when they do, they often tend to deal with the material they find interesting and put the rest aside to ‘deal with later’.
The following tips may come in handy in winning the war on paperwork:

- Handle paper once. Deal with it then. For example, if you receive a request for information on the group, immediately get all the appropriate information together in an envelope ready for mailing.
- If you are requested to make comments on a short document, do so immediately after reading it. This also applies if you need to make some decision based on a document.
- Do the things you least like doing first. For example, common practice is to first read enjoyable material, like newsletters containing articles of interest, or material that doesn’t involve decision-making. Leave this material as a reward for when you finish with the not-so-pleasant things.
- Keep chipping away at big (and possibly boring) jobs like reviewing and commenting on the local mental health service’s quality assurance policy of 500 pages. Devote half an hour a day to such tasks.
- Distinguish between what is ‘urgent’ and what is ‘important’. Consult the plan you have developed and stick to it. Remember that, within the plan, you have put aside time (20 percent) to deal with urgent issues. Attend to the urgent issues first and then get onto the important issues according to their priority.

**Defining personal administration problems**

- Are you sure what your goals and priorities are?
- Are your goals realistic considering your other activities?
- Do your goals fit with your values?
- Are you avoiding anything?
- Do you have trouble deciding what is ‘urgent’ and what is ‘important’?

Answers to any of the above questions may be one of the following:

- You may need to clarify or reconsider your goals and priorities,
- You may be trying to achieve too much and may have lost some focus,
- You may need to be more assertive in order to say ‘no’ to requests to do urgent work (for example, to people who ask for comments on a 500 page document by the end of the week),
- You have a decision to make, which you are avoiding,
- You need to restructure ‘work time’ – put a DON’T DISTURB sign on the door,
- You need to delegate some of your work to others,
- You are so tired you can’t think clearly – have breaks and give yourself a reward.

(Also see 3.10: Note-taking and minute-taking and 4.7: Organisational administration.)
Introduction
Communication is the passing of information from one source to another. Interpersonal communication is passing on information from one person to another. This information may include facts, feelings, attitudes, opinions, instructions, desires, as well as other things. This section of the Kit concentrates on the interpersonal communication skills which individuals and groups undertaking advocacy activities most often require.

Negotiation
Often people think of negotiation as a specialised skill used by people such as diplomats and business people for specific situations. In reality, negotiation is used by every one of us every day of our lives. For example, young children negotiate with their parents at the supermarket checkout (buy me this packet of lollies now or I’ll make such a fuss you’ll never want to set foot in this place again); parents negotiate with their children to eat their vegetables; friends negotiate how they will spend the weekend; car buyers negotiate with the salesperson on the purchase price.
In many organisations today, staff and consumers participate in many of the decision-making processes. Wherever there is power, and wherever decisions need to be made, negotiation skills are used. It doesn’t matter if the relationships between people are competitive or cooperative, negotiation techniques are required. Most people work within a team and negotiate with each other on a daily basis. Most people report to a ‘boss’ with whom issues are negotiated on a regular basis.

Elements of negotiation

A fairly simple but effective model of negotiation is one presented in a training video entitled *Agreeing to Agree* by the English comedians Smith and Jones. According to this model there are four stages in negotiation.

● The first stage is called PIG, which stands for:
  • Prepare before you start – have an idea of what you want to achieve,
  • Identify the issues – try and anticipate the other person’s position,
  • Gather information – ask a few questions.

● The second stage is called IIK, which stands for:
  • Invent options when you reach a stalemate,
  • Inter-relate the issues – you’ll consider this if he or she will consider that,
  • Keep saying ‘if’, for example, ‘If it makes things easier for you ...’.
  (Also see 1.3: Assertiveness – the ‘broken record’.)

● The third stage involves developing alternatives:
  • Your position is much stronger if you have an alternative line of action,
  • Try to show the other side there is somewhere else to go.

● The fourth stage is to aim for a fair agreement:
  • A negotiation is not a battle but an agreement,
  • Negotiation is not about winning or losing – be firm and be flexible,
  • Ideally an outcome will be reached that will satisfy both parties.
Skills
A good negotiator is a good communicator. All the skills of a good communicator are brought to bear in the negotiation process. These include expressing ideas clearly; being open-minded; being a sensitive and active listener; making sure that feedback occurs; knowing how to ask open questions. A skilled negotiator avoids getting personal, keeps emotions in check and focuses on the issues rather than on the person.

Environment
The physical environment in which negotiations take place can influence the outcome. To improve the chances of negotiating successfully, strive to create the most conducive environment. For example, ensure that the negotiation takes place in a quiet environment without any distractions; that the number of people for both sides of the negotiation are proportionately equal and that the seating arrangement does not create a disadvantage. When the North Vietnamese and the South Vietnamese finally sat down together to start negotiating after the Vietnam War, the first thing that had to be resolved was the shape of the negotiating table. Both sides considered it absolutely vital that they were seen to be on an equal footing. There could be no ‘head of the table’, so they used a round table.

Before commencing a negotiation, it is necessary to decide what sort of impression you want to give the other person in the negotiation. A friendly, verbal approach may be the best way to go, and in many cases it is. However, if you already know that the person you are negotiating with does not like such an approach, and actively despises people who adopt friendliness in the deadly business of negotiation, then it is wise to modify your non-verbal messages to suit the occasion. People often mirror the behaviour they experience. It is important, therefore, for you to establish the non-verbal environment and to try and maintain it, even if the person you are negotiating with wants to adopt a more aggressive or belligerent form of communication.

Non-verbal body language to look for when negotiating
1. Keep an eye on head movements. If you look carefully while you are negotiating you can tell whether your message is getting across.
2. Listen for non-verbal grunts. By listening for these you can determine whether they are agreeing with you or not.
3. Look at facial expressions.
4. Maintain eye contact. This is very important when negotiating. The power of looking directly in another person’s eyes can sometimes be almost overwhelming. You can also draw conclusions about the other person by observing where their eyes are focused.
5. Watch the other person’s gestures. If they are open and expressive the chances are they are being honest.
6. Look at the person’s posture. A person who sits up and leans forward is enthusiastic and confident. A person who slumps back is showing lack of interest.

Successful negotiators have a positive attitude. They are able to view conflict as normal and constructive. The skills negotiators use to resolve conflict can be learned and, once learned, can provide the confidence necessary to challenge others and initiate a positive negotiation. Understanding the skills of negotiation is sustaining when people are challenged by others. Attitudes influence people’s objectives, and objectives control the way they negotiate. The way people negotiate determines the outcome.

Success
A successful outcome in negotiation includes:
- Meeting the needs of each party,
- Resolving conflicts fairly,
- Offering durable results.

Studies show that successful negotiators are those who:
- Have higher goals or expectations of the outcome,
- Obtain consistent small concessions,
- Are unpredictable with their concessions.

Conflict
Conflict is important in negotiation as it leads to solutions, agreements and teamwork. The aim of conflict in this process is for collaboration not compromise. Collaboration means that both parties are happy; compromise may lead to both parties being unhappy. Although the word ‘conflict’ generally conjures up negative images, in negotiation this does not necessarily have to be the case. In fact, most change is dependent on some form of conflict. (Also see 1.12: Conflict resolution/mediation/complaints.)

There are two forms of conflict: destructive and constructive. Destructive conflict is the refusal to deal with causes of conflict, for example, the Northern Ireland situation. On the other hand, constructive conflict is where the idea of a resolution is never ignored.

Sometimes a resolution may not be reached. In the preparation stage of the negotiation, alternatives to the outcomes sought need to be determined, as well as the point at which you walk away from the negotiation. This is sometimes referred to as BATNA (Best Alternative To a Negotiated Agreement). In other words, have a pre-arranged counter plan. The negotiation need not be considered a failure as much will have been learnt through the process.
Facilitation

Facilitation is often thought of as the act of making something easier or less difficult to achieve. Facilitation can be defined as a set of activities that help individuals or groups perceive, understand and act upon the ‘process events’ that occur in their environment. ‘Process events’ are the plans and methods developed to apply to specific events in life. For example, learning assertion skills is a process event, while using these skills on a rude person at the theatre is not. Facilitation does not mean actually carrying out the act itself; rather it is a process of clarification which allows others to be able to carry out the act themselves. For an individual facilitator it stands to reason that his/her work with a particular group is time limited and not a permanent part of the group structure. A good facilitator is one who is continually working at doing themselves out of a job.

Facilitation goes hand-in-hand with empowerment. One person cannot empower another; the best the person can do is to facilitate the other’s empowerment. Facilitation is often carried out by individuals, such as a facilitator of a forum or workshop. Facilitation can also be carried out by a group as a whole, through the provision of services which facilitate a positive change in the attitudes of others. For example, this Kit is designed to be facilitative, rather than an instructional manual on ‘how to do it’. Whether facilitation is carried out by a group or an individual, there are a number of skills and strategies required for individuals to be effective.

Group facilitative skills

Individuals within groups can have facilitative skills. This is especially the case for user-run groups which operate in a democratic way with a focus on empowerment. The skills which individuals within such a group use to seek solutions to problems, gain agreement, correct errors and follow group process can be called facilitative skills. They are facilitative because they don’t provide solutions to specific issues; they facilitate a process which can be applied to any number of issues. Four facilitative skills which can be applied to many of the issues that groups encounter are:

● Problem-solving (also see 1.4: Problem solving),
● Gaining consensus (also see 4.5: Team development),
● Self-correction,
● Managing process (also see 4.5: Team development).

As three of the skills listed above are covered elsewhere, only the facilitative skill of ‘self-correction’ is dealt with here.

All groups make mistakes. Groups which have self-correcting skills also make mistakes, but they have an in-built process to correct them. They learn from their mistakes and don’t keep making them. By learning as they go, a group can generally avoid making a mistake from which they cannot recover. A self-correcting group realises that all endeavours are a form of continuing education. A time is not reached where a group can sit back and say: ‘Well, that’s it, we’ve finally got to the point when all our problems are over’.
The following suggestions are designed to assist a group in confronting problems constructively:

1. **Communicate openly**
   Group members need to be able to have open, frank discussions about the problem. All members must be willing to speak up about problems and listen to each other’s perception of the problem. This can be carried out if there is trust between fellow group members. People are vulnerable when speaking out about what they perceive, and can really only do so in an atmosphere of good faith. Where such an atmosphere exists, real learning can take place.

2. **Find the problem, not someone to blame**
   For a group to be self-correcting, problems must be viewed apart from personalities. When members look at someone to blame, defensiveness and mistrust take over. For a group based on empowerment and facilitation this has obvious disastrous consequences. The problem needs to be examined objectively.

3. **Examine what you are doing**
   Engaging in process evaluation examines not only what the group does, but how it functions. This means taking time to review the past to plan for the future. All individuals, groups and organisations that wish to grow must take time regularly to determine what is working and what isn’t.
Facilitative leaders

One of the fundamental core components of an empowered group or organisation is not an individual ‘achiever’, but the coordinated group of individuals who operate together as a team. All members of the group understand the role they play in the group, but are free to ‘achieve’ in their own right. The leader of the empowered group is not a person who makes decisions on behalf of the group and then issues instructions to others, but rather, is the person who is in charge of the personal development of the group; the person who creates the environment for learning and development. This type of leader can be called a facilitative leader.

The facilitative leader helps the group develop a learning environment. This means that the group carries out its activities in a way that not only gets the job done, but does it in such a way that the group understands how it is done and how to do it again more effectively. The key is not simply getting the job done, but learning how to learn. An action by the group may have a successful outcome if the group merely carries out the instructions of someone else without facilitation. However, because group members do not know why the action is successful, they will not be able to replicate this success in other situations.
Being a facilitative leader requires a number of skills and abilities, including:

- Focusing on process, not content,
- Enabling, not controlling,
- Being a coach, not an expert,
- Sharing power, not hoarding it,
- Being a learner, not a teacher,
- Being supportive, not critical,
- Understanding intra-group processes (events which happen within the group),
- Understanding inter-group processes (events which happen between groups).

The goals of the facilitator are to help the group make an informal assessment of its situation and to help the group develop its own action plan. A crucial assumption of facilitation is that problems stay solved longer and more effectively if the group solves the problem itself. The facilitator has a role in passing on assessment and problem-solving skills, but does not attempt to solve problems alone.

To maximise the involvement and sense of ownership on the part of the group, facilitators must be flexible listeners, analysers and presenters of information. For example, a knowledge of intra-group processes can help everyone to participate, including those who are having difficulty in expressing themselves and whose views might otherwise be rejected as invalid. Such knowledge and skill may help in preventing the leadership role in a group becoming stuck with one or a few dominant individuals, even though a number of members may wish this. Other relevant skills include those of someone who facilitates the written collection of members’ ideas and the analysis and subsequent presentation of these ideas. (Also see 4.4: Leadership.)

**Listening and absorbing information**

Interpersonal communication is not just about passing on information. Equally important is receiving or listening to information. Quite often the message a person is attempting to send does not get received in the way it is intended. There may be a number of reasons for this, but the major reason is often that the receiver is not listening attentively. In negotiation and facilitation, in fact in a lot of the work you may be doing, effective listening is vital.

Below are some listening habits which human beings all engage in some or a lot of the time. For many people the following habits are bad habits in that they prevent effective listening. However, some people do find that some of these habits are not so bad. For example, one prominent doodler finds that her doodling increases her ability to listen and process information. If you find that the examples don’t apply to you, simply ignore them.
1. Lack of concentration

People are capable of listening and absorbing ideas at a much faster rate than most people talk. On average, people can talk at a rate of 125 words per minute, yet can easily think at the rate of 400-500 words per minute. The difference between speech speed and thought speed is often responsible for much of people’s distraction. Instead of concentrating on the speaker’s message, the mind frequently uses its excess capacity to think about other things generally a lot more pleasant than what is being listened to. For example, at the same time as you listen to a conversation, you can think about plans for the week or that guy or girl you want to get to know a little better. Before long the mind has wandered far away and completely ‘tuned out’ to what the speaker is saying.

Solutions

● Try to anticipate what the speaker will say,
● Focus on the message – search for deeper meanings,
● Review what has been said,
● Ask questions as an aid to remembering,
● Look for the development of ideas and arguments,
● Look for patterns and organisation in the way information is presented,
● Take time to reinforce the speaker’s message.

2. Avoiding difficulties

Many people stop listening if they think the speaker is going to talk about something technical or difficult to understand. In today’s society, people are conditioned to evade difficult material. You only have to look at what is offered on television to see that this is the case. This is the age of ‘escapism’ where there’s a widespread tendency to listen to only light, recreational and unchallenging material.

Solutions

● Discuss the topic being spoken about with a person you enjoy being with who you respect,
● If possible, ask the speaker for an explanation of meanings, theories, principles,
● Read about the topic to increase your interest.

3. Criticising the speaker

The speaker’s appearance, delivery, dress, mannerisms or eccentricities may all inhibit listening. People can feel defensive listening to a person who appears young talking on a topic where they feel they wouldn’t have experience. People can query the reliability of a speaker with untidy hair and extremely poor taste in clothing, but looks can be deceiving. When people react to speakers in this manner, they are not listening effectively and are short-changing themselves by closing the door on what may be useful information.
Solutions

• Be aware of your beliefs and ideas and try not to let them stereotype people,
• Remember that every single individual has their own thoughts and opinions,
• Recognise when prejudice and bias are influencing your perceptions of the situation,
• Remember that mannerisms are a part of an individual’s personality,
• Remember people like Albert Einstein and Charles Darwin were unimpressive in appearance but had important messages that changed the world.

4. Faking attention

People often only go through the motions of listening and reason that, if they pretend to listen, no one will notice the difference. However, the mere act of pretending may actually require as much effort as listening. There is no sense in making this effort and remembering virtually nothing. While individuals may think they are doing a good job of faking, they seldom fool the speaker. The speaker can tell by their reactions that they haven’t absorbed a thing of what’s been said. This is likely to not only affect communications in the future, but to affect the speaker’s attitude towards them.

Solutions

Everyone at some time (some do it a lot of the time) pretends to be listening attentively when in reality they are miles away in thought. It’s really much more appropriate to either make an effort to listen and learn, or to walk out if, after careful consideration, there appears there’s nothing to learn. Time is limited. Don’t waste it, and don’t waste the time of others.

5. Emotional word interference

Established beliefs and ideas also govern how people listen. Religion, politics, race, sex, and nationality are all potential minefields of reactionary material as most people feel strongly about at least some of these areas. In some instances individuals can be very inflexible about such matters. Whenever they feel that established and cherished beliefs or ideals are threatened by others, they either refuse to listen or their emotions may block and interfere with the process of listening.

Solutions

● Good listening does not imply that people need to agree or accept what is communicated – they need to try to understand ideas so that they can decide whether or not they agree with them,
● Practise tolerance towards others,
● Try to recognise when prejudice and bias are influencing perceptions of the situation and make a conscious effort to hear the words and ideas which are upsetting.
6. Impatient listening
Often when someone is talking others are waiting impatiently to have their own say. It is probably true to say that many people like to speak more than they like to listen. When this occurs, they concentrate more on what they are going to say than on what the speaker is saying.

Solutions
● Be patient,
● Listen to the whole message before questioning or commenting,
● Control the urge to interrupt,
● Try to understand the speaker’s point of view first, and then present your ideas calmly and logically.

7. Prejudging the subject
When first listening to some speakers, people are often quick to declare the subject to be boring. This can occur because previously such a topic has been boring, or because there is no information on the subject at all. The most exciting or attention-arousing subjects are those in which people are personally interested. If the subject doesn’t immediately appear to directly involve them, or seems boring, they may go off at a mental tangent, feeling that there is no reason to listen.

Solutions
● Try to recognise when prejudice and bias are influencing our perception of the subject,
● Make an effort to listen to new ideas,
● Look for ideas that have some relevance or even minor interest for you so that you do not leave empty-handed,
● Prepare for listening to increase comprehension and interest,
● Remember the key to good listening is to ask: ‘How can I use this information?’ Sift and sort the wheat from the chaff; that is, hunt for worthwhile ideas and facts to use.

8. Obsessive note-taking
Look around a room where a talk or lecture is being given and you will see people furiously taking notes in an attempt to record everything that is being said lest some important little pearl of wisdom be lost. The problem with this is that all people are left with are written words. They may have lost the context in which the words were spoken and quite often they have been writing so quickly that they can’t even decipher what they have written. If they can make out what the words are they often can’t work out what it all means. Note-taking does not necessarily mean writing down every single word that is spoken.
Solutions

● Develop your own form of short hand – as long as it works for you,
● In a group, allocate the task of note-taking to one person who is good at it and the rest can watch and listen,
● Make sure that you catch the messages the speaker is sending which written notes may not convey, such as excitement, happiness, anger,
● Make brief and meaningful notes,
● Develop a flexible and accurate technique.

9. Mentally debating with the speaker

People tend to look for weaknesses in arguments, especially if they are knowledgeable about a particular aspect of a topic or have experience in that area. One minor weakness in an argument can start a mental debate, where a counter-argument is planned. As a result, the rest (and maybe the best) of what the speaker has to say is missed.

Solutions

● Listen to the whole message,
● Jot down a few words to remind you of the point you wish to discuss, then concentrate on the speaker,
● When the speaker has concluded, prepare what you want to say and at the appropriate time have your say. If someone else has brought up a similar point, you can always add your own comments to further highlight the point in question,
● Again, try to recognise when prejudice and bias influences your perceptions of the situation.

10. Creating distractions

It’s often easy to get distracted when listening to others talking, especially if it is a long meeting or seminar. Even if you are tempted, don’t talk or carry on discussions with people near you (or far away). Resist temptations to shuffle paper or do things which you know makes you lose concentration.

Solutions

● Don’t sit with people you may be tempted to talk to,
● Don’t take things with you that may cause distractions,
● Resolve to write down only important things like facts, figures, principles.

11. Tolerating distractions

The other side of the coin is being able to tolerate distractions. It’s inevitable that distractions will occur. The trick is to minimise the impact of these on your listening ability. A failure to grasp many of the other listening skills listed here will decrease the ability to handle distractions. Poor listeners are easily distracted by other sounds or sights going on around them.
Solutions

- Arrange your environment to eliminate distractions as much as you can. For example, select a seat in the front row; if the person next to you has the flu, move to a different seat.
- Modify environmental factors that are preventing you from listening effectively. For example, if there’s a lot of noise coming in through an open window, ask for the window to be shut.

12. Poor posture

Speakers respond to listeners who look at them, remain alert, make encouraging sounds and ask intelligent questions (that is, questions which tell the speaker that people are listening and interested, and questions which encourage the speaker to give additional information). People who slump sideways with their head in their hands and their eyes closed do not give any indication of interest.

Solutions

- Don’t slouch, slump or sleep in your chair,
- Sit up and look alert,
- Expect the best outcome, not the worse,
- Establish and maintain regular eye contact and nod your head if and where appropriate.

Rules for good listening (for those who like rules)

- Don’t talk
- Show that you want to listen
- Remove distractions
- Empathise with the speaker
- Be patient
- Control your emotions
- Selectively moderate your argument and criticism
- Ask questions
- Summarise, review and reflect
- Look for areas of interest
- Don’t let the speaker’s personality or mannerisms overpower the message
- Listen to both verbal and non-verbal cues
- Actively concentrate on the meaning of the message
- Take notes where appropriate
- Relate new information to what you already know

References

Elder B (1994) Communication Skills, Macmillan Education Australia, South Melbourne
Smith M & Rhys Jones G (date unknown) Agreeing to Agree, (video)
Many, many books have been written on ‘how to influence people’. Is it possible to cover all the skills required for this in these pages? Definitely not. However, many of the sections in this Kit also have a lot to do with influencing people and these are listed at the end of this section.

Individuals and groups engaged in advocacy activities are all about influencing others. This is the fundamental aim of such activity. Very broadly, there are three sets of factors that determine how well attempts at influencing people turn out:

- The characteristics of the **communicator**,
- The characteristics of the **communication**, and
- The characteristics of the **audience**.

**The communicator**

The communicator is the source of the message. Characteristics of the communicator which relate to his or her ability to influence people may include:

- Degree of passion
- Life experiences
- Credibility
- Expertise
- Trustworthiness
- Status
- Age
- Voice qualities

**Credibility**

Studies show that communications from a credible source (such as a consumer saying what it’s like to suffer from stigma), have a greater influence on people than communication from a source with no credibility (such as a doctor talking about what it’s like to suffer from stigma).

**Personal relevance**

If a topic is personally relevant, the audience is more influenced by the arguments and less influenced by certain characteristics of the communicator.
Speech style
Communicators with relatively high levels of hesitation and hedging (for instance, ‘well, maybe, I’m not sure’) are often perceived by the audience to be low in competence and persuasiveness. Speakers who talk confidently at a fairly moderate rate and in a clearly audible voice, are generally perceived to be competent and persuasive.

The communication
Characteristics of the communication, or message, include:

- Empathy,
- Degree of passion demonstrated,
- Emotional appeals (anger, disappointment, fear),
- Novelty (freshness of ideas),
- Presentation style (dramatic, humorous),
- How the arguments are presented – are both sides presented or only one side?
- Repetition.

Repeated exposure
Up to a point, repeated exposure to objects or people results in increased liking. This is why, at election time, politicians are out and about non-stop, kissing unsuspecting babies, popping up at the supermarket and on the television. In fact, examining the amount of media exposure may predict which candidate will win office. On the other hand, overexposure can occur if a person or object is always ‘in-your-face’, and can lead the audience to becoming negative towards that person or object. Those cheap, boring and in-your-face ads on TV often prompt people to swear that they will never buy the product. The solution to exposure is to provide balance.

One-sided vs two-sided arguments
When trying to influence an audience about an issue, the communicator has to decide whether to present a one-sided argument (for instance, ‘by adopting this policy these positive benefits will be achieved’), or a two-sided argument (for instance, ‘by adopting this policy, many positive benefits will be achieved, although there may be a few negative impacts that need to be considered’).

The answer lies in understanding the nature of the audience. If the audience is likely to be supportive of the message, then the one-sided message can be most effective. However, if the audience is made up of critical sceptics (who have probably thought of a number of negative impacts), then the two-sided argument is better. Preparation is the key. Think of arguments that people may come up with and develop counter-arguments in advance.
The audience

The characteristics of the audience which affect its ability to be influenced include:

- Life experiences
- Degree of passion about the topic
- Intelligence
- Involvement
- Memory
- Expertise
- Personality (that is, how easily they can generally be influenced)
- Age

When trying to influence an individual or a group, you have no control over these characteristics of the audience. However, you can do a little research on the type of audience you want to try to influence. For example, if you are at a university conducting a workshop for medical students undergoing psychiatry training, you may suspect they will be critical and questioning of your social justice arguments for a new model of mental health care.

In such a situation, you can present yourself and your arguments in a way that has the greatest impact on this particular audience. Find out the kind of information they are being taught, so that you can develop counter-arguments and be ready to confidently justify them. For such an audience, you may decide that a two-sided message may be the most appropriate.

Also see:

1.3: Assertiveness
1.6: Interpersonal communication
1.10: Family involvement in service delivery to consumers
1.12: Conflict resolution/mediation/complaints
2.5: Managing change
3.6: Submission writing
4.4: Leadership
5.6: Lobbying
1.8 The business end of participation

Do you need a business card?

Many people are happy to receive all work offers through organisations or groups to which they belong. It is, however, common for people who have seen you in action to ask for your contact details so they speak to you directly rather than go through your organisation. Think carefully about whether or not you wish to give out personal information, including your home address and/or phone number. You can give your details verbally or you can write them down each time you are asked. If you are actively seeking more work, you may find it useful to prepare business cards and distribute them widely.

- Many shopping centres have machines that you can use; or you can approach a professional printer; or buy blank cards from a newsagent and hand write or stamp them with your details. It is possible to have stamps made quite cheaply to use on cards as well as to prepare letterheads and put your return address on envelopes. You can also obtain stamps that you make up yourself and change if necessary. Some computer programs and printers can also be used to make cards.

- It is useful to include a short description of what you do on the card, for example, Consumer/Carer Consultant, Mental Health

- Be sure that you take your cards with you wherever you may meet people who may offer you work; don’t be shy about giving them out when talking to people (‘networking’) at conferences, forums or meetings.

When people give out cards they usually include work addresses and phone numbers. If you are home-based, you may choose to put less detail on your card, or even to give your organisation or group contact details instead of your own. This is a useful way to protect your privacy. Other things to consider when deciding what information to put on a card are:

- What is the most efficient way of contacting you during business hours?
- Are you home enough to catch calls that come in?
- Do you have an answering machine?
- Do you have a post office box?
- Are you happy to give out your home phone number and/or address to strangers?
- Do you have an e-mail address or a mobile phone number you can use instead?
Negotiating a fee

Consumer/carer consultancy may involve working across diverse settings and with unsalaried individuals or representatives of community groups. It may also involve working with members of professional groups who command salaries that range from moderate to very high.

How should consumer and carer consultants decide what ‘value’ to place on their services in such a situation?

One way of going about this is to charge for services according to the guidelines set out for casual consumer consultancy by the relevant State or Federal governments, and to keep this rate fixed, regardless of the situation within which work is being done.

The first practical problem with this approach is that the rates set by State and Commonwealth governments are calculated differently. The two rates compare as follows (using Victoria as an example):

Victorian State Government casual Consumer Consultancy:
$20.00 per hour; $70.00 per half day (4 hours); $130.00 per full day.

Australian Federal Government Sitting fees as set by the Remuneration Tribunal:
$140.00 per half day (3 hours); $235.00 per day (5 hours).

It needs to be noted that all of these rates operate on the assumption that consumer consultants will do some preparation and debrief work in their own time. Some payment schemes take account of travel time and expenses; others do not. It makes sense for consumer consultants to think carefully about how much time they are actually putting in.

The second problem might be described as a matter of altruism (regard for others). Most consumer/carer consultants find themselves doing unpaid or voluntary work from time to time. This may be because they feel passionately about one or more issues that they want to work on and there is no money available to pay for their work. Alternatively, work that consultants have been paid for doing sometimes blows out beyond the allocated budget, but they choose to work extra unpaid hours to achieve the desired ‘outcome’.

The third problem can be described as a matter of fairness. Is it fair that a consumer/carer consultant who is matching wits in a meeting or on a panel or as a public speaker with highly paid medical professionals, managerial consultants or media celebrities, receives a fee which is a fraction of theirs? The short answer to this is ‘no’.

Is it fair that one or two consumers or carers in paid work positions rely on the unpaid labour of numerous others to achieve acceptable outcomes? Once again, the short answer is ‘no’, but the solution to this problem is complicated.
Some people think a so-called 'Robin Hood sliding scale' is a useful way of solving a few of these problems. According to this scale, you take the government-suggested fee rates as a starting point for a per person minimum fee in consumer consultancy. Then if you find yourself thinking about or actually working in groups with highly paid professionals (hopefully not as the only paid consumer or carer), consider:

- Are you expending as much (or more) energy than they are?
- Is your contribution (at least) as worthwhile as theirs?

You may decide to charge for your services accordingly. Find out what the other participants are earning (by contacting professional associations or the relevant administrative associations, or by asking them directly, if you have that kind of relationship). Since such behaviour on the part of consumers/carers challenges the existing economic standard, you may encounter a lot of resistance. If you do, it can be useful to compare notes with other consumer/carer consultants individually or via consumer and carer organisations.

If you find yourself working in groups with other consumers/carers – some paid, some unpaid – you might like to talk together about ways of spreading the money around more fairly. Some people have experimented with doing this, but description of the many issues involved is not possible here.

### Some practical money matters

Once a fee for your services has been negotiated, the question of how to obtain payment arises.

Larger organisations and institutions may have specific forms for you to fill in and may require a tax file number or bank account details in order to pay you through their systems. It is useful to carry this information with you when working so that any forms can be completed on the day of work.

**Never leave without knowing how you will be paid.** Try to obtain a contact phone number and an idea of when payment can be expected so that any late or missing payments can be chased up.
Other organisations and groups will ask you to submit an invoice to them for the agreed fee. It does not matter if this is handwritten or typed, but an invoice must include the following:

- Your name, address and contact phone number,
- Name of the group from whom you seek payment,
- Date the invoice is prepared,
- Date(s) worked,
- Number of hours worked (if payment is based on an hourly rate),
- Rate of payment (hourly, daily, other),
- A short description of the type of work done,
- Total amount owing,
- Your signature.

Printed invoice books are available at most newsagents and can be very useful, as a copy of the invoice stays in the book. This makes record-keeping easier, especially if you do a lot of work. If you prefer to write your own invoice the following sample is a useful guide:

**Sample Invoice**

From: Judy Citizen  
123 Main Street  
Large Town 9999  
Phone: 9999-9999

To: Relevant Organisation  
456 Busy Road  
Large Town 9999

Date: 9/9/99

For: Participation in ‘Really Important Meeting’

On: 8/8/99  
2 hours at $30.00 per hour

Total now owing - $60.00

Signed: Judy Citizen

Judy Citizen
People who do a lot of work may find it useful to number their invoices so that cheques received can be easily matched up with the relevant invoice.

Everybody should keep a record of invoices sent and forms filled in to make it easier to chase up any payment that fails to arrive. This may be a full copy of the invoice or the main details may be noted in a book or diary. You can determine whether you have recorded enough detail by asking yourself the following question:

**Can I produce a copy invoice or form from this information if the original is lost?**

Be sure that you match all payments received to their invoices. This way you can tell which need to be chased up and also have good records of income received.

### Taxation and the Department of Social Security

Important reasons for keeping good records are income tax and/or Department of Social Security (DSS) requirements. Both of these require you to have full details of monies earned over a period of time.

Remember that payment on your invoices or forms is rarely taxed by the people paying you and, therefore, group certificates are not issued. It is your responsibility to keep good records and to be aware of any taxation implications so that you can be prepared to pay any tax owing upon assessment. The Australian Taxation Office has enquiry numbers printed in the phone book, so do your research.

If you receive DSS benefits, you need to familiarise yourself with income-reporting requirements relevant to your benefits. These requirements vary widely depending on the type of benefit received. Things to find out from your documentation or DSS office are:

- How much can be earned before benefits are affected?
- Is the benefit taxable or not taxable (that is, how does extra income affect tax liability)?
- At what earning level do benefits cut out altogether?
- At what earning level or length of time after losing payment is concession eligibility lost?
- How is income to be reported?

Only you can decide how much paid work to do, so it is important to know all the possible implications and to balance your workload and income level.

Each DSS benefit is different, so find out about the right one. For example, with some pensions, income over three months is averaged and the benefits received over the following three months are reduced if appropriate. This can cause extra hardship if the excess income has already been spent. Other benefits are affected in the next fortnight. It is vital that you know exactly how your personal situation will be affected by any earnings so that you can plan and budget accordingly.
For all DSS benefits there is a level of income below which your payment is not affected. Your payments will be reduced by a percentage (usually 50 cents in the dollar) for each dollar earned above the ‘income-free threshold’. At a certain income level, DSS payments cut out altogether. These levels differ across the different benefits. Whether you do all of your invoices at once or invoice for each job may be a critical factor in how your benefits are affected, so, once again, do your homework.

Some people do not report their income. This is risky and may have serious implications for continuation of benefits, possible imposition of penalties and requirement to return money overpaid.

Ignorance of DSS requirements is no defence if you are caught doing the wrong thing, so it’s best to get the information you need directly from the Department of Social Security.
Creating a personal advocacy plan

This Kit is about advocacy. It is about those actions that individuals and groups can take to deal with the injustice, infringement of rights and inequity that affects them. It is about empowerment of the individual. In mental health advocacy, there are times when consumers are less able to pursue self advocacy. This is particularly so in situations where disempowerment is more evident, for example, upon admission to a psychiatric unit.

It may be useful for you, as a consumer, to adapt this tool to your own needs for the times when you want another person to advocate on your behalf. You may be aware of occasions when you are not able to represent your own views and needs in the way that you like. One of the risks at these times is that people around you may assume they know what is best for you and exclude you from exercising choice.

Consider adapting this tool to your own needs. You will not be able to cover every event, but organising somebody to advocate on your behalf before you need them may ensure that what they do remains empowering to you. You can write down the main points to provide some authority to the person acting on your behalf. Even with such written authority, you cannot guarantee that it will be respected by the people with whom you want the person to negotiate. The real strength in the agreement is in discussing your needs with the person you choose and talking through the dilemmas and issues that both of you may face. Choose somebody you trust and can talk to freely.

Expect only that the person will act in your best interests to the best of his/her ability. Remember too that they also have to care for themselves. Don’t demand of them more than they can give. Sometimes they will try their best but still not achieve what you want.

Ian plans ahead

Ian knows he is going through an unstable period. There are a number of times recently when it seems necessary for the crisis team to visit. On one occasion he is taken to a psychiatric unit for two days. He knows he is still not well and is concerned, as the last time he went to hospital he was unable to get people to tell him the things he wanted to know. He is already having trouble keeping his affairs in order and is scared that if he goes to hospital for a longer period he might forget to do something important.

He gets on well with a support worker from the local psychiatric disability support service. Together they discuss Ian’s concerns that he does not want to feel out of control if he needs to go to hospital, and what his preferences are. They agree to jointly sign a personal advocacy plan.
Personal Advocacy Plan

Sample

Name: Ian Smith  Date: 11/6/98

I would like you (name of person) Perry Mason
to represent my rights under the following circumstances:

• If I become ill and am in need of crisis team assistance or end up in hospital,
• If I express to you that I am being unfairly treated because of my mental illness,
• When you observe these symptoms (list them).
  • ..........................................................
  • ..........................................................

I trust you to act in my best interests to the best of your ability.

I want you to:
• Consult with me regularly,
• Assist me in understanding my situation,
• Ask questions of doctors and other staff on my behalf to assess that my treatment
  is fair and reasonable,
• Remind me of the things that might need to be attended to, such as rent, so that I
  can organise through you or another person ways to attend to these matters,
• Contact my case worker or the crisis team if she is unavailable.

I do not want you to:
• Tell anyone about my condition unless I give permission (including my family),
• Call the police,
• Notify my ex-wife.

Signed........................................................Date ..................................................

I agree to act as your advocate under the stated conditions. We have discussed
the best way for these things to happen. I agree to act in your best interests to
the best of my ability.

Signed........................................................Date ..................................................
Yuri’s parents wanted to make a difference but were unsure what to do

Yuri has been admitted to psychiatric hospitals on a number of occasions over the past four years. When he was first admitted he lived with his parents. After the second admission he moved into a group home and shared with other people who live with mental illness. Generally, he was satisfied with the arrangements. He had no difficulties with the other residents, although he didn’t have a lot to do with them. He attended some programs at the local day centre and a support worker met with him once a week. His psychiatrist considered him ‘reasonably stable’ but was not satisfied that the treatment provided was still right. He was considering one of the newer medications now available. Yuri tended to appear unwell at times, particularly when stressed. He enjoyed spending time alone, listening to music and writing poetry, and sometimes chose to do this as an alternative to attending the day centre. He smoked heavily and sometimes went to the local hotel for a drink. Without cigarettes he became agitated and sometimes he ran out of money. He was a frequent visitor to his parents’ house, coinciding with periods when he had no money. His parents considered him to be quite demanding of them.

Yuri’s parents had seen him through many years of a developing mental illness. Initially, they could not understand what was going on. Their local doctor put it down to anxiety associated with pressure at university and prescribed some tablets. The situation worsened and Yuri was eventually sent to a psychiatric hospital, a period of trauma during which he was angry with his parents for what he saw as their part in it. Yuri’s parents learned a little about the illness, the treatments and what they could expect, mainly through ad hoc discussions with the ward staff when they visited. They often felt, though, that the workers they spoke with resented their involvement. Yuri’s parents had resolved to continue to support him even though they did not always know if they were doing the right thing. Providing Yuri with additional money was one way they knew they could support him, but they were not wealthy themselves. The burden of Yuri’s increasing requests was making them angry. They feared that if they said too much they might drive him away. This was not what they wanted.

Box continues on the next page
Yuri’s story continues...

As they discussed the problem together, they agreed that if Yuri were attending the day centre more often he would not smoke so much, he wouldn’t go out drinking, he wouldn’t be able to isolate himself with his own thoughts, and he would improve. If he didn’t keep turning up asking for money, they might have a different and better relationship with him. They decided to ask for an appointment with his psychiatrist to tell her what they thought Yuri needed.

Just as all families are not the same, not all service providers are the same

There is no standard response by service providers to carers. Some will be attentive, some will understand, some will be responsive, some will not seem to care. This makes it difficult to know what to expect. It’s often useful to get to know them as individuals rather than perceive them to all be the same.

Be clear about rights and expectations

Contemporary mental health service models tend to recognise the importance and value of family member involvement. Australian mental health policy recognises the right of carers to respect and to information, education, training and support. It also recognises the right of carers to be consulted by service providers about treatment for a consumer with the consent of the consumer. The National Standards for Mental Health Services state that: ‘The treatment and support provided by the mental health service is developed collaboratively with the consumer and other persons nominated by the consumer’.

You should expect, at the very least, a fair and respectful hearing. Your advocacy activity may aim at more than this. You can anticipate that most service providers will acknowledge and may even be helpful around your personal needs, but guarded in discussing the needs of the consumer, unless permission has been obtained.

Examine your own motives

Be clear about why you are seeking representation. Is it because you feel ‘they’ are not doing enough for the consumer? Are you angry about your own sense of powerlessness but wanting to express anger at ‘them’? Do you want to say how it is for you and see if somehow your needs can be supported?
Examine your own needs and values

Your needs are not the needs of the consumer. They are intimately entwined but different. Often, resolution of ‘what he needs’ can appear to be the way to solve your problems, but you cannot guarantee it. The result may be a different set of circumstances that are no less tolerable.

Take the time to think about what you want for yourself rather than what you want for the consumer. Representing your own needs to a service provider can gain you support that you had not previously considered. It may provoke some analysis of the situation that the service provider had not thought of that, in turn, can benefit the consumer.

Consider what your concerns and criticisms are directed towards. Is it in response to some injustice that demands to be exposed, a right that has been infringed, an abuse that has been perpetrated? These are issues towards which advocacy activity must be directed. Is it in response to something that you have difficulty accepting; that it is not the way ‘it should be done’ but nonetheless is what the consumer wants? Consider your own values and the extent to which they are the driving force behind your concerns. Denying the consumer the right to adopt a different set of values may be, in itself, an injustice.

Express what you know and acknowledge what you don’t know

Family members know the consumer intimately. They have often experienced the course of the condition and are expert observers of small signs of positive and negative change in the consumer. Begin by saying that you do not expect the service provider to divulge any confidence of the consumer. Be prepared to state what you know in a clear and concise way. Service providers tend to value good information. Ask the service provider to also respect your confidentiality.

Be open to new knowledge. Anticipate that service providers may respond from a different experience of the consumer that is equally valid. Consumer recovery can place family information out of date. This is particularly true when people are not living together.

Remember that, for many service providers, the consumer’s interests come first

While service providers may respond respectfully to family members, they are likely to see the consumer as their primary focus and not want to be drawn into compromise over the consumer’s best interests. Anticipate that the service provider will want to maintain privacy and confidentiality about many aspects of the consumer, unless prior permission has been obtained. (Also see: The challenges of advocacy in the Knowledge and Attitudes Booklet)
You may feel inclined to challenge notions of confidentiality asserted as in the best interests of the consumer. Such a strategy carries with it risk of further withdrawal of interest by the service provider or rebuke by the consumer if your strategy is successful. Advice and support for your decision may best come from a carer support group. Ask for a referral.

Service providers are well placed to understand your needs and to provide advice. Consider that the focus on the consumer may compromise the service provider’s capacity to meet your personal needs. It is usually best to separate out your support needs through independent personal counselling.

You may want to think about entering a partnership with the consumer and service provider around mutual needs and to seek personal support from another agent, say a carer support group. This is one way of separating out the issues and not creating compromise.

**Accept responsibility for your own actions, not those of the consumer**

In the end, you can only determine your own actions and be responsible for them. The choice the consumer makes is his/hers, even if that choice is unacceptable to you. Engaging in a partnership with the consumer and the service provider legitimises your involvement in influencing outcomes.

**Negotiate with the consumer, set the conditions**

In determining and accepting responsibility for your own actions, you are asserting your own rights. This includes your right to be respected and not to be abused. Family members can sometimes feel that the actions of the consumer infringe this right. Taking stock of what is acceptable to you will enable you to assert your position. You can determine what is acceptable to you and be clear to the consumer about this.

Asserting change in a relationship in this way is not an easy task. A mutual partnership between carer, consumer and service provider is helpful. In addition, independent support and advice from a carer support group can be of immense value.

The worksheet in 1.11: Reaching agreement with significant people, may be useful as a basis for agreement.
Yuri’s parents meet with the psychiatrist and get angry about how Yuri is ‘allowed’ to spend all his money and to spend so much time on his own. They come away frustrated that the psychiatrist seems to be siding with Yuri. She has given them the phone number for a carer support group.

Yuri’s parents attend the support group. They begin to appreciate that they are not alone. They also realise that if they negate the ‘reason’ for Yuri coming to see them (that he needs money), they run the risk of losing him completely. This is not acceptable to them. In considering their own needs, they come to realise that their greatest concern is not to live in fear of Yuri’s threatening behaviour or of losing him. They need to learn how to assert their own rights and to respect those of Yuri.

They tell Yuri they want him to continue to visit but that they aren’t happy with the way things are. Yuri agrees for them all to meet with his support worker, with whom he has a good relationship. While the first meeting is tense, they all manage to get through it without getting too upset or blaming each other. Yuri’s parents, at least, determine that they are simply going to say how it is for them and hope that the support worker can facilitate a good outcome. They agree to a subsequent meeting at which Yuri’s parents state the conditions under which Yuri can visit. They agree to support his income with a regular allowance providing he agrees to their conditions. Yuri says he will agree as long as his parents stop ‘nagging him’ about the way he conducts his life.

The support worker encourages Yuri to tell his parents about his recovery program and the choices he is making. He is particularly pleased to tell his parents that some of his poetry is being used in a brochure for staff training. The support worker suggests that the agreements are stated in writing and that everyone has a copy. Yuri’s parents continue with the support group and attend an education program that helps them to better understand many aspects of Yuri’s condition.

References
Reaching agreement with significant people

It is sometimes difficult to untangle individual needs and to show respect for each other’s rights, particularly in the relationship between a consumer and his/her family members. It is not unusual for conflict to emerge. Often this is because people have not taken the time to identify what their independent needs are and how the actions of the other person impact on them. Once done, this simple tool can be adapted to record explicit agreement on the actions that each person is going to take.

Using this type of tool is only appropriate through agreement. Both parties need to take the opportunity when they are calm and rational and have thought through the issues. Consideration may need to be given to finding a mutually acceptable person to mediate an agreement. It may be useful for the person to also have a copy of the agreement in case reminders are necessary.

Using this type of tool provides the opportunity for dialogue to recommence. Attention can again be given both to individual needs and the impact of certain actions from both parties. Writing out an agreement may merely confirm arrival at mutual respect.
Agreement

Sample

I (name of person) Colin Bates agree to do this:

- Contribute my agreed share of money for board,
- Keep my appointments with treating teams and medical people,
- ............................................................

Not do this:

- Not play music after 11pm and keep the noise to a reasonable level at other times, or use headphones,
- Not smoke cigarettes in the house,
- Not bring illegal drugs into the house,
- Not demand money or use abusive and aggressive language to my parents,
- ............................................................

I (name of person/s) Ron and Doreen Bates agree to do this:

- Respect and treat you as an adult,
- Support you when you are unwell in the following agreed ways,
- ............................................................

Not do this:

- I will not consult with your doctor without your permission unless I firmly believe your life is at risk,
- ............................................................

We both agree to review this agreement on (date) 4/5/99 by:

(Describe the process and who is to contribute)

- Meeting with the support worker and being clear that we are all satisfied.

Signed........................................................Date.................................................
Signed........................................................Date.................................................
Signed........................................................Date.................................................
1.12 Conflict resolution/mediation/complaints

Conflict can occur within all committees, groups and organisations. It can be minimised by having pre-established ground rules. (Also see 4.5: Team development). However conflicts and complaints can still occur. As well as having ground rules, it’s useful to have mechanisms in place to handle conflicts and complaints. These are sometimes referred to as ‘grievance procedures’ or ‘complaints procedures’.

It is important to remember that conflict within a group is not necessarily bad. When managed effectively, conflict can lead to high quality group decisions and improvement in group functioning. When handled ineffectively, conflict can demoralise members, reduce work performance and block goal achievement. Group leaders require ability to diagnose different types of conflict and the stages in their development, and to develop skills in methods of conflict resolution.

Types of conflict

Once the basic issue has been identified, the group leader needs to find out the type of conflict this is causing. The conflict may be open and obvious to all. For example, two group members may openly disagree with each other and argue almost continuously. Or, two group members may never talk to each other and the conflict may not be noticeable. For example, two group members may appear to get on but, behind the scenes, they continually undermine each other.

Of the three types, the first is probably the easiest to deal with. It’s already out in the open and the two people in conflict can readily agree that there is a problem. The last type is more difficult to deal with. The two people may deny there is even a problem. However, no matter which type of conflict is occurring, there can be considerable damage to the group.

Phases of conflict development

When the type of conflict has been identified, the group leader needs to determine the phase of conflict development and the seriousness of disagreement. The first phase is where those in conflict identify the issues that divide them and show their feelings about those differences. In the second phase they explore similarities, acknowledge agreement on certain matters, and identify some positive feelings towards one another. While it is quite easy to see which phase the conflict is in, it’s more difficult to see if the first phase has just begun, is well progressed or is nearly completed. If attempts are made by the group leader (or a mediator) to begin the second phase before the first phase has been completed, the conflict resolution will be short-lived.
Severity of conflict

The severity of a conflict can be judged by noting the frequency and duration of encounters between those in conflict, the emotional level of these encounters, and the extent to which they can discuss the problem. If the conflict is serious, appears to be getting worse, threatens other members of the group or interferes with the work of the group, the leader needs to intervene immediately to reduce the conflict and confine it to as few members as possible.

Intervention in conflict

Having decided that intervention is needed, the group leader must then decide whether he or she has enough mediation skills or is the appropriate person to mediate the conflict. It may be more appropriate to bring in a person from outside the group as a mediator.

The next thing to decide is when to intervene. The leader should not intervene in a serious conflict situation at a time when there is little hope of conciliation. If both people in conflict believe they are in the right and neither is willing to listen to the other’s or an outsider’s point of view, then resolution at that point has little chance. The mediator at this point needs to postpone intervention until those in conflict demonstrate a more receptive mood.

If conflict is of long duration, affects group morale unfavourably, but is not severe, the group leader may not intervene to deliberately cause the conflict to increase and come to a head. This may motivate those in conflict to actively seek a resolution.

For either an experienced or an inexperienced conflict mediator, deciding what to do and how to do it requires careful planning. The best means for relieving conflict between individuals is to eliminate the basic cause for the dispute. This may be difficult to do if conflict is long-term, because a lot of other issues will be drawn into the dispute, including the different perspectives of other group members and the possibility they will take sides. If the basic conflict issue cannot be identified, the mediator may concentrate on emotional issues that separate those in conflict.

This may be done by working to either suppress conflict by preventing open expressions of hostility (for example, ‘Jenny, if you keep calling Bob a “fat, lazy mongrel” you will be asked to not attend any further meetings’), or by insisting that those in conflict state their negative feelings in an appropriate manner (for example, ‘I believe that Bob is not pulling his weight in the group and this upsets me’).

Conflict in negotiation

Conflict is important in negotiation as it leads to solutions, agreements and teamwork. The aim of conflict in this process is for collaboration not compromise. Although the word conflict generally makes us think of negative images, in negotiation this does not necessarily have to be the case. In fact, most change is dependent on some form of conflict. There are two forms of conflict: destructive and constructive. Destructive is the refusal to deal with causes of conflict, for example, the Northern Ireland situation. Constructive is where the idea of a resolution is never ignored.
Grievance procedures

It is essential for groups involved in advocacy activities to have grievance procedures. These need to be for people outside of the group who may have a complaint against a member of the group, as well as for members who may have a complaint about decisions from within the group. Some suggestions for standard grievance procedure steps include:

- Attempt to resolve the grievance with the person directly,
- Document all grievances raised, even if they are resolved informally,
- Inform the committee as soon as a grievance is made,
- If the person has been unable to resolve the issue informally, the grievance should be put in writing to the committee,
- The committee acknowledges the grievance in writing within one week of receiving it and sets up a meeting with the parties involved to attempt to resolve the grievance,
- One month after receipt of the grievance in writing, all steps should be completed,
- If the grievance is unable to be resolved within the group, other mechanisms for resolving the grievance must be pursued. An example of another mechanism is to ask someone with mediation skills from outside of the group, and unknown to members, to mediate.

Also see:
1.6: Interpersonal communication
1.7: How to influence people
4.4: Leadership
4.5: Team development

References
Preparation and organisation are two of the keys to successful advocacy and participation. This section of the Kit focuses on skills and strategies which can prepare individuals and groups for effective involvement in advocacy.
It is essential that all people who make a decision to be involved in advocacy work (whether paid or unpaid), give some thought to how they can protect themselves from being totally swamped by the political, economic and social realities which will surround them. The fire of personal experience often drives those who are involved in advocacy. It is this very fire, while being the catalyst for their involvement, that has the capacity to immobilise them if not treated with respect. Careful attention to adequate briefing and debriefing procedures is essential as part of a strategy for political survival. (Also see 1.1: Looking after yourself.)

‘To be burned out, you have to have been on fire.’
Graham Hyde, Hospital Executive, Consumers’ Health Forum Conference on Quality, 1995

**Briefing (familiarisation)**

Consumer and carer participants, in whatever capacity and whether paid or unpaid, are entitled to adequate, clear information about their role.

If you have been invited to sit on a committee, you need to be fully informed about the purpose, powers and responsibilities of that committee. You are entitled to receive relevant information in plenty of time before meetings so you have time to consider the topics for discussion.

If you are taking up a staff position within services or commencing work as a volunteer, you are entitled to a full and clear job description and information about your rights and responsibilities.

Consumers and carers participating in research projects need to be informed about research design, methodology, confidentiality and any other key elements. If you, as a consumer or carer, are carrying out the research, you need to provide full and clear information to anyone with whom you are working.
Individuals and groups who have been asked to run workshops or other educational activities need to be informed about where their contributions fit into the wider educational curriculum. This is necessary for planning presentations and for ensuring maximum impact.

Adequate briefing includes administrative detail such as:

- Can you get your travelling expenses reimbursed? How? Can you have a taxi voucher?
- Who will meet you and show you where to go? When and where will you be met?
- How do you get paid? To whom do you address your invoice?

You may have to be assertive about making sure that you have been adequately prepared for what you have to do.

In some situations, the information that is sent out might be difficult (or even impossible) to understand. Consumers and carers may be diffident about complaining about the inadequacy of such cryptic ‘information’, but here are some things that you can do:

- Contact the person responsible for organising the event and ask her/him what the main issues are? Ask what the person thinks might be the major areas of controversy or debate. Although this person may have a perspective which differs from your own and from those of other participants, you will, at least, gain some idea of the agenda.
- If there are two consumers/carers involved, go through the papers together. Sometimes the information you read starts to make more sense when you talk about it. However, this is extra preparation time for which you may not get paid.
- If you are involved in some kind of decision-making committee, you can try contacting other members who share your perspective and/or priorities.
- It is a good idea to attend any social activities arranged in conjunction with the event. These can be opportunities for a great deal of informal decision making. If you have not been invited to these informal activities, you may be at a serious disadvantage.
- In some committee situations you may not get your briefing papers until the last minute. It is a good idea to speak to the person responsible and give a polite reminder of the difficulties created by their late receipt. Sometimes people working in big organisations forget (or do not know) that consumers and carers may not have easy access to phone, fax or e-mail facilities. It is a part of your work to educate them about the need to accommodate community members of committees, and so on.
Debriefing

One of the most important pieces of wisdom to come out of the consumer and carer movements is the need for debriefing.

Debriefing involves talking through things you have done, heard, seen, experienced, with the purpose of clarifying your thoughts and feelings about them. When you ring up a friend to share a painful or pleasurable experience, you are actually debriefing. However, in the context of consumer/carer participation, there is a need for some kind of organised debriefing where the ‘listening’ role can be carried out by someone who is familiar with the kinds of experiences being described; that is, someone with a consumer or carer perspective.

Even though some kind of semi-formal debriefing session is often called for, there are occasions when a group of consumer/carer workers can find it useful to engage in an informal debrief at the local coffee shop or pub.

The role of the listener is precisely that – to listen. It is important that the listener puts aside any critical or judgemental thoughts and listens in an accepting and caring manner. The listener does not interrupt, start talking about their own experiences or give advice. The listener provides a safe environment in which the speaker can work through his/her thoughts and emotions to a more comfortable state of mind. The ideal situation is where people working in pairs take turns at being the ‘listener’ for each other.

Debriefing is necessary because consumer/carer participation is often emotionally difficult, over-stimulating, disturbing or all of these at once. Without an opportunity to ‘talk through’ experiences, consumers (and sometimes carers) can become overwhelmed by thoughts, worries and memories. In some cases this can lead to illness.

Debriefing is particularly important after telling your story in public, perhaps for the first time. Storytelling can be seductive as well as scary. Politically experienced consumer presenters have found that, at times, they have been drawn into public ‘tellings’ that might better have been avoided. (Also see 3.2: Telling stories.)

Public speaking can be a difficult experience for anyone, but for consumers and carers there is the added impact of stigma. One consumer described it as, ‘feeling like I had just taken my clothes off in public. What was funny was that it felt alright at the time. It was later that I started to feel sick’.
It is always a good idea to organise to meet with someone after a public storytelling occasion. This is a strong argument for working in pairs or in small groups. If this is impossible to arrange, make a phone call to someone you trust just to let them know how you experienced the session.

As consumers and carers get more experienced and more confident, they will start to invoice services, universities and other organisations for paid debriefing time as well as for preparation time. As well as a way to ensure appropriate payment for the work involved, this sets an example of good practice for less experienced people and for organisations employing them.

References
Wadsworth Y & Epstein M (1996) Orientation and Job Manual: Staff-Consumer Consultants in Mental Health Services, VMIAC, Melbourne
This book is available from the Victorian Mental Illness Awareness Council, 23 Weston Street, Brunswick VIC 3056, phone 03 9687 8317.
2.2 Identifying and overcoming barriers

Consumers and carers know only too well the barriers people with relatively little power face when trying to influence those with a lot of power. These barriers need to be overcome if the individual or group is to be successful in their endeavours. The first step is to identify the barriers that need to be overcome.

Identifying barriers

Individuals can undertake this process themselves. However, it’s best done in a group where different ideas and perspectives can lead to a more comprehensive outcome.

Barriers are all those factors which get in the way of the individual or group successfully carrying out the work they are undertaking.

Barriers might be identified through personal experience, knowledge of situations where the barrier is identified, or through reading or hearing stories from others. A distinction needs to be made between known barriers and potential barriers (those which may possibly occur). First concentrate on the known barriers.

For example, below is a list of identified barriers to effective consumer participation on boards and committees:

- Incongruency between stated values and actual practice (that is, people say one thing but do another),
- Tokenism,
- Lack of representativeness (or the perception of its lack),
- Role strain (for example, where a fellow committee member may also be your treating doctor),
- Poor communication,
- Economic factors.

Once a list of barriers is made, identify the ones which have the greatest negative influence on the work you are undertaking. Next, make a list of those barriers which can be addressed most readily. In the example given above, consumers and carers on the committee may be able to prove quite readily that they are as representative (and possibly more representative) of consumers and carers generally, as the service providers on the committee are of service providers generally.
Overcoming barriers
The easy bit has been done: the barriers have been identified. Now plans and strategies need to be developed to overcome them. To keep morale up, it’s best to start with the barriers there’s a good chance of overcoming. Work with only one barrier at a time. The following ideas may be useful:
- Define and describe the barrier,
- Describe the problems that result from the barrier,
- Describe who or what benefits from the barrier,
- Generate possible solutions for the barrier.

Example: Process to overcome barriers

Define and describe the barrier
Your group cannot obtain funding through the Department of Family and Community Services. The Department does not recognise the group as an advocacy group eligible for funding, as its definition of advocacy doesn’t conform to the Department’s definition of advocacy.

Describe the problems that result from the barrier
Your group has only limited funding which prevents it from undertaking a lot of work covered by its mission statement. This is creating a morale problem as members feel that the group is set up to do advocacy, yet it is being refused funding as an advocacy group.

Describe who or what benefits from the barrier
Your group feels that the Department in question benefits, as it is saving money that should be going to groups such as yours. The group also believes that the targets of its advocacy work also benefit, as there is less opposition and exposure to what it is doing.

Generate possible solutions for the barrier
- Lobby the Department in question to change their definition of advocacy,
- Begin a campaign, in collaboration with others, against the Department,
- Modify the group’s definition of advocacy to conform to the Department’s,
- Look for alternative sources of funding.
The steps suggested above may be carried out through a number of ways. Below are some ideas on creating a productive environment:

- Work together as a group, making sure everyone has a say,
- Use ‘brainstorming’ tactics,
- Use ‘cause and effect’ tactics; that is, ‘if we do this, what will be the result’,
- Collaborate with others who have similar barriers,
- Consider using an external facilitator who may assist in providing objectivity,
- Work in a room with plenty of space,
- Write everything up on large pieces of paper (such as butchers paper) stuck to the wall, so that ideas aren’t lost,
- Find out as much information as possible about the issues related to the barrier and those presenting the barrier,
- Invite to group meetings people with knowledge on the decision-making processes of those presenting barriers (this is vital information),
- Find out how widespread the barrier is – is it just happening to your group, or does it occur all over the world?

What’s required for overcoming barriers

Remember and use the 4P rule:

- Persistence,
- Patience,
- Providing alternatives,
- Personal support.

Dealing with frustration

In overcoming barriers, there will be a lot of frustration. Some barriers may take years to overcome. Many consumers and carers have been battling for decades to overcome barriers with only marginal success. However, for major barriers such as ‘tokenism’, even marginal success is a great achievement.

List the barriers that the group has overcome. Remember that, in forming a group, many barriers have already been overcome. Determine why the group has been successful in overcoming these barriers. Consider if this can be applied to other barriers.

An effective way to deal with frustration is to maintain a proactive stance. In other words, don’t accept that change is only in the hands of others. Be passionate and go after the group’s objectives. Set the agenda and make others react to the group’s proposals.
2.3 Dealing with conflict of interest

Conflict of interest emerges when you are:
- Likely to make personal or business gain out of a situation that otherwise requires you to act according to other purposes or responsibilities,
- Compelled to act in a way that is not in keeping with your preferred way of acting.

Conflict of interest can arise in a number of ways in carrying out advocacy activity. What is regarded as a conflict at any particular time is not absolute.

Nguyen is an independent consumer consultant with a developing track record in policy advice and mental health service evaluation. He is a member of a working group deciding the best structure for evaluation of a new service. It is decided to release the evaluation project through competitive contract to an external consultant. Nguyen is approached by a consulting company to be a team member in a bid to undertake the work. Nguyen is very interested in undertaking this work but is also aware that he has been privy to information through the committee that other competing teams do not have. Clearly, his use of the information places his team in an advantageous position. Additionally, as a committee member, he will be compromised if he is asked to contribute to selection of the consultant.

Maria is a carer representative on a management committee for a disability support service. The service has become aware that it is not providing sufficient access to most people. The service is considering moving its rehabilitation program to another suburb more central to the area of greatest population. Maria’s daughter attends the program on a daily basis and where it is currently situated is readily accessible. The new location will complicate travel arrangements for Maria’s daughter. It appears that the only resolution will be for Maria to take her daughter to the train station every morning. Maria knows that the service is insufficient and inappropriately placed. At the same time, she wonders how she will personally be able to manage the new arrangements.
Colin is asked, as a consumer, to be on a selection panel for a new worker. When he turns up for the interviews, he discovers that one of the applicants is his cousin who he knows has been out of work and is desperate for a job.

Helga is aware, in her capacity as an independent consumer consultant, that a small group of influential people is negotiating for a policy change that will have negative implications for large numbers of consumers. She knows that the consumers in the action group, of which she remains a participant, will want to challenge the advice being given by these people if only they know about it.

Conflict of interest poses a dilemma for the person involved. It often represents choices between two or more courses of action, each of which can close off an opportunity. Conflict of interest may remain a more personal issue, as in Maria’s case; have broader ramifications, as with Nguyen; in Colin’s case it may be more subtle in relation to any advantage for him; and for Helga it may create the risk of personal anguish, disloyalty and potential loss of business. Sometimes these are enormous dilemmas with no ready resolution. A few simple strategies are worth considering:

- Central to the resolution of a conflict of interest is to expose it at the earliest opportunity to those people who will be affected by the issue. Trying to keep it under wraps, even during a period of indecision, can create difficulty. Another person may expose it first and can, even though your non-exposure is innocent, cause you embarrassment and some loss of confidence from others. Even if you are not sure if it is a conflict of interest, any doubt is worth exposing.

- Choose not to speak on the issue. If you are a member of a committee, you may elect simply to not contribute to, or vote on, the issue. In some situations it may be best to absent yourself from the room while that particular issue is being discussed. In other situations, say where you are dealing with confidential information, it may be best to simply state that you are subject to some privileged information and are not in a position to discuss it.

- Talk it through with a very trusted friend who will maintain confidentiality.

- Act as a link between interested people so that an issue can be exposed without compromising your position.

- Make a decision. It may be better to withdraw completely from one of the courses of action.
Good information improves advocacy activity. Having information leads to knowledge and, both knowing something and demonstrating how you know, is empowering.

Mental health advocacy may require access to a broad range of information from a person’s own clinical file through to general information on particular topics.

Useful general information is accessible to the public through libraries, government departments and the Internet.

Sometimes information is subject to confidentiality provisions and is not made public. If you believe you have a case for gaining access to confidential information, your particular State or Territory may have legislation that supports your access. If you are not sure about this, your local mental health legal advisory service or other legal advisory service can tell you.

**Gaining access to your own clinical file**

Usually, the facility that holds your clinical file has a policy for administrators and staff to enable a consumer to read that file. If a policy exists, expect it to represent the prevailing legal position of your State/Territory. Even as legislation moves progressively towards ease of access to information, for instance Freedom of Information legislation in relation to government departments and bodies, anticipate that local policies will lean towards restrictive practices. Some policies will be more formal than others and inevitably the policy will need to be followed.

Using legal avenues for accessing your file may be preferred where you don’t want to negotiate with the service provider; the service provider may have refused you access or perhaps older files that are not kept by the service provider are required.

Before seeking access to your file, take into account that:

- Some consumers have said that looking in their files was one of the most empowering experiences they have had,
- Full or partial access may be denied,
- Strenuous effort, including legal representation, may be required to move your request further,
- You may not like what you read, including inaccurate representations and labelling,
- You may need to question whether you have the strength for such an onslaught.
Getting Organised

2.4 Finding relevant information

If you choose to proceed, local policy will sometimes require that a staff member sits with you to assist. You may want to choose a staff person with whom you have a good relationship. If you are not used to reading clinical files, having such a person available to you is particularly useful in finding your way through the various parts of the file. The staff person will also be in a position to assist you to understand the technical language and jargon that appears in these files. Depending upon your particular requirement, you may want to negotiate for a third person of your choosing to assist you and provide impartial advice and emotional support. Organise some debriefing for yourself. (Also see 2.1: Briefing and debriefing.)

Before reading the file, you may find it useful to consider a number of key questions to guide you through it:

● What do I want to know? (for example, have staff written about you fairly?)
● How will I make my own judgement? (for example, you may want to consider what words or phrases you consider ‘fair’ and ‘unfair’.)
● How will I record my observations? (for example, making notes of what is in the file or how the staff member has interpreted a comment to you – some facilities allow photocopying of all or parts of the file.)
● What do I want to do with the findings? (for example, write a letter of praise or complaint.)

Make notes for yourself about the process of gaining access to your file: the things that you and others had to do; the dates that things were done; who was involved in decision making; the good aspects and the difficult aspects. You may want to use your experience to promote change to improve access for others in the future.

Exploring service issues

Your interest may be in understanding more about government health policy or local mental health service development. Depending upon your needs, your State/Territory health department is likely to have published statements about a range of service policy and strategic directions. A phone call is often all that is required.

The Commonwealth Government makes its public documents available through the Australian Government Info Shops in the States and Territories. Government policy documents are increasingly being made available on the Internet.

A potentially easier option is to check out what the various consumer and carer organisations have. Many of them retain libraries of local interest and these may include books and articles on broader areas of interest.

Local mental health services create their own internal documentation that will be of relevance to advocacy activity at that level. Evaluation reports are often enlightening. Develop a group of knowledgeable people around you. Being part of an organisation can assist in this. As you engage in discussion with people around advocacy issues, you will identify those with particular information that is of value to you. Over time, you may develop a circle of informants with whom you can regularly share new information.

Groups can invite service providers, policy makers and organisational representatives to present information at meetings.
Reviewing the literature

Advocacy activity is frequently about creating a case or argument for a particular cause. To be effective, it is important that the argument be based upon sound knowledge of the issues. Strength of argument is frequently acknowledged when it is supported by reference to published works on the subject. These are known as ‘the literature’.

The library is a good place to commence the search

- Municipal libraries are useful sources of information for general topics. Library staff are able to assist with a search for information and can demonstrate how to use the various catalogues and the computer database to find what you need.
- Municipal libraries are generally restricted to immediate access to the more popular books on subjects of general interest. They also have reference book sections that may prove useful as a starting point on a topic.
- Municipal libraries will also have local research reports and population information from the Australian Bureau of Statistics. They may be able to assist with gaining access to references not immediately available to them.

Talk to a librarian

- Mental health advocacy is usually about some special topic that is beyond the immediate scope of municipal libraries. Many of the psychiatric hospitals or general hospitals with psychiatric units maintain a limited library to which access may be obtained. A discussion with the librarian is a useful starting point.

Consider specialist libraries

- The most useful sources of specialised information are the libraries of the various State/Territory departments of health and the universities that teach mental health subjects.
- As a general rule, access rights to these libraries are restricted to departmental staff and students of the respective university. However, government department libraries will often grant access rights to affiliated organisations like consumer and carer groups. As a member of such an organisation, you can take advantage of this.
- You may find that the consumer or carer group itself maintains a specialised library with all the information you need.

Consider access to legislation, government policy and the various guidelines and discussion papers that are produced

- The specialist libraries will have much of this available. In addition, the particular State/Territory departments can assist in locating particular papers that have been produced. Your local mental health legal service will be able to assist.
Consider the status of papers

- Not all of the papers will necessarily be for public consumption while they go through various drafting, discussion and approval stages. When using or quoting particular papers, it is important to know the status of the document – whether it has no formal status within the department, is for promoting discussion only or is formally endorsed. To use an informal document as the foundation for a cause, may weaken an argument.

Have some idea of what you are looking for

- If you know the particular book or article by title or by the name of the author, then finding it is fairly easy.
- If you want to undertake a general library search for everything you can on a particular topic, it is best to consider ‘key words’ as this is the way that catalogues and computer databases find things. If you want to find books and articles on ‘advocacy’, for instance, your first key word may well be ‘advocacy’. If you ask a library computer to find everything available on ‘advocacy’, it will scan its database that may well be international, and return literally thousands of titles to you. This is clearly too much but it is a starting point.
- Narrow your search by being more specific. You can, for instance, ask only for ‘mental health advocacy’. This will narrow your search to only those articles that are recorded as such and may be what you want. However, given that ‘advocacy’, as a subject, is broader than ‘mental health’, it may also exclude a lot of useful articles. You may decide, therefore, that ‘advocacy’ is not the best key word and choose instead, for instance, ‘consumers’ and ‘carers’. By narrowing these searches down, you may arrive at a list of useful articles on ‘mental health advocacy’ from a different entry point.
- The value of computer-based searches is that any one of them takes only a matter of seconds to give you a list of headings. You can keep searching until you find what you want. The librarian will usually be pleased to assist.

Consider how you want to access physical copy

- Your list of titles will not usually tell you whether the books or articles are what you really want. You can gain more information from a computer database by asking for ‘abstracts’ of each of the articles. This may help in deciding whether or not to find and read the article.
- Having decided on your final list, which can usually be printed out for you, you can then find the books and articles in the library. If the library does not have them, the librarian can usually get them for you upon request. Sometimes there may be a fee attached.
- Depending on the arrangement you have with the library, you can borrow books and photocopy articles. Again there may be a fee associated with photocopying.
Accessing the Internet

The Internet is an increasingly accessible source of information

- To access the Internet, you will need a computer, a modem connected to a telephone line (your ordinary line is sufficient), an Internet Service Provider (ISP) and appropriate software.
- Your local library may have free Internet access. You will need to book in advance to use it.
- Some of the consumer and carer organisations and non-government service providers also have Internet access that may be accessible to you.

If you have your own equipment, you will need to purchase services from an ISP

- There are large numbers of ISPs that advertise in papers and magazines. The ISP is the link between your computer and the ‘World Wide Web’.
- ISPs charge for their services, either as a flat rate or for the amount of time used. Prices vary enormously. You will need to determine the best deal for you before registering with an ISP. Ask around from people you know before committing yourself.
- Your ISP will usually provide the software required for Internet access. Because of the way ISPs bill, you will probably need a credit card.

Searching the Web is a matter of trial and error but there are ‘search engines’ to assist

- As with library searches, you need to type in key words and request a search. The time it takes to receive a response depends upon the speed of your computer, the speed of the telephone connection and how busy your ISP is.
- Having viewed the response, you may wish to narrow the search by altering the key words or start a new search. The Web connects to every computer that has put information onto it from anywhere in the world.

As well as using the Internet to collect information in a similar way to that of a library search, there are other important information-gathering features. One is through e-mail mailing lists, another through newsgroups.
E-mail

- When you register with your ISP, you will be given your own e-mail address that enables the exchange of messages between you and anyone else with an e-mail address.
- Several Web-based e-mail services are also available – ‘hotmail’ is one example. These services can provide private e-mail addresses using public Internet terminals, for example, at the library or a community organisation.
- One feature of having an e-mail address is that you can subscribe to e-mail mailing lists through your personal e-mail facility. People subscribe to a mailing list about a particular topic of interest, say, mental health consumer issues. Every time a subscriber types a message to the mailing list, it is distributed to every other subscriber. Subscribers then may choose to respond to the message and every subscriber will receive the response. In this way, subscribers can engage in information exchange through a type of ongoing discussion.

Newsgroups

- Each newsgroup covers a single topic of discussion. Messages are posted by participants for all to read.
- You will need an additional piece of software, a newsreader, to access the newsgroups. Some of the Web browsers provided by the ISPs contain newsreader software. You can then access all the messages of a newsgroup, download them to your computer and read them at your leisure. You may then want to follow up on an article by posting your own message or to reply directly to the person who posted the article via e-mail.

Chat groups

- Internet Relay Chat (IRC) enables users to talk to each other in real time, using their keyboard to type messages. There are many discussion topics to join, including plenty on mental health issues.
- When you type and send your message, it is delivered on screen to all the people participating in the group. They, in turn, can reply to you straight away. As well as group discussions, private discussions can occur at the same time.

References

Neely M (1997) *The Big Pond Internet Companion*, Maxibooks, Australia

A list of some starter Internet sites is provided on the next page.
Some starter Internet sites

- For e-mail listing, try the
  OZMAD site: http://www.madnation.org/ozmad.htm

- General mental health sites
  Internet Mental Health: http://www.mentalhealth.com/
  Mental Health Net: http://www.cmhc.com/
  Psych Central (John Grohol’s page): http://www.coil.com/~grohol/
  Psychiatry and Mental Health: http://www2.cybernex.net/~jas/index.html
  PsySpy: http://idealista.com/cgi-bin/hts-v2.99?psyspy.hts
  Depression Central: http://www.psycom.net/depression.central.html

- Psychiatric Treatment Sites
  RxList (International Drug Index): http://www.rxlist.com/
  PharmInfoNet Drugs Database: http://pharminfo.com/drugdb/db mnu.html
  Psychopharmacology Tips: http://uhs.bsd.uchicago.edu/dr-bob/tips/tips.html
  Shocked! 40,000 Volts of Fun (ECT page): http://www.il.net/~juli/shocked.html

- Action/Activism/Advocacy Sites
  MadNation: http://www.madnation.org/

- Other Sites
  MacArthur Research Network on Mental Health and the Law:
  http://ness.sys.virginia.edu/macarthur/
  Royal Australian and New Zealand College of Psychiatrists:
  http://www.ranzcp.org/
  Australian Transcultural Mental Health Network:
  http://ariel.ucs.unimelb.edu.au/~atmhn/
  SANE Net: http://home.vicnet.net.au/~sane/
  Disability Discrimination Act:
  Human Rights and Equal Opportunity Commission:
  VICNET Disability Page: http://www.vicnet.net.au/disability
People advocate for things to be different from the way they currently are, or to maintain things as they are in the face of pressure for them to be different. All advocacy activity causes people to confront change.

In advocacy, change is both a personal thing, related to individual responses to change, and an organisational thing, in relation to how organisations respond. To the extent that organisations are a collective of individuals, change in organisations is complicated by the multitude of personalities involved. The individual’s response to change also relates to the importance to them of their relationship to the organisation.

Simon faces resistance to change

Simon is a member of a non-government disability support service and a user of its ‘Art Studio’. He is an accomplished artist in his own right and, from his own experience, values the contribution of self-expression through art to the process of recovery. The service lacks the resources to supply additional artists to open the studio for more than two half-days a week. Simon knows from talking to other users that demand is high. He considers the idea of the studio opening an additional half-day. His notion is that people should be able to gain access to the studio for the purposes of self-expression without the need for workers to be in attendance. He is confident he can ‘caretake’ the studio himself.

Simon discusses his idea with the manager of the studio who is supportive but ‘isn’t convinced it can work’. It is suggested to Simon that he needs to gain additional support. He raises his idea at the consumer committee, speaks to consumer members of the committee of management, and discusses it with the manager of the organisation. The collective advice is that, while nobody objects to the idea ‘in principle’, some staff are concerned that this might be the start of a larger move for consumer-run services. In order to become comfortable with him ‘running the program’ some consumers need to confirm that Simon has not become a ‘professional’.

The committee of management is looking for a way to ensure that a good idea is not lost while maintaining harmony within the organisation. Simon suggests that he be a part of a working group with consumers and staff, to make sure all the issues are raised and an agreed resolution is found. The group decides to support an additional half-day with initial staff support.

During the transition phase, Simon and a nominated staff member run the first three sessions together before Simon takes it on himself. The small group of consumer participants continues to attend the program and develops a strong rapport through discussion about consumer issues as the art works take shape. They begin to wonder why they had expressed concern when the original idea was put forward.
Even when faced with the strongest reasons for change, people and organisations tend to demonstrate predictable responses. These responses vary from different forms of resistance through to differing levels of acceptance. Resistance to change may be about tentative approval through to outright confrontation. Acceptance of change may vary from passive resignation to an unavoidable reality through to enthusiastic embracing of a new way of doing things.

Change in mental health service delivery systems and decision-making structures has been consistently sought by consumers and carers. The shape of current structures is often determined by a strong investment in particular organisational design and determined by institutional history. While change appears difficult, some systems and structures are undergoing major transformations.

At the same time, consumer and carer movements are constantly establishing and reinventing themselves. There is consistent internal and external pressure on consumer and carer organisations to take stock of their positions. They are in the midst of change.
Change and the person

Even for those managing or advocating for something different, change creates anxiety, uncertainty and stress. Change affects a person’s self-esteem and performance. New systems have to be learned. There is no guarantee that the new approaches will work and, often, irritating snags will have to be worked out on the way. Managing change involves a lot of effort in dealing with problems and dealing with the doubts of others.

Some people experience discomfort in trying to maintain a particular role in the face of a range of pressures. They may not be involved in the decisions that affect them, they may have insufficient organisational support, new technology may have been thrust upon them, maintaining standards may be difficult, people around them may be uncooperative. The sense of responsibility to achieve in the face of uncertainty can become overwhelming.

Some people respond to change by becoming motivated, seeking and driving the opportunities that may be there. Others become autocratic as a way of containing their issues. Many become lethargic and resistive.

Resistance to change is a common occurrence. It is an initial reaction through which people can be led. Some of the signs of resistance are:

- Caution and scepticism,
- Apathy,
- Lack of interest in, or perceived incentive, to change,
- Lack of involvement and participation in the changes,
- Open, and even hostile, distrust of the motives for change.

Managers sometimes foster resistance to change by dealing with people as if that is the response they expect. Resistance needs to be understood and endorsed, in the first instance, to allow people to be engaged in change. Managers need to communicate that resistance is anticipated but that things need to move on.

Change can have substantial negative effects on the individual. They may include:

- **Loss of security** – perhaps the person fears they will lose their job,
- **Loss of competence** – some people may be expert in their field and then find that what they are good at is no longer required,
- **Change in relationships** – the change may require people to form new teams and leave the old ones behind,
- **Loss of sense of direction** – ‘I knew what we were striving for; now I’m not so sure’,
- **Loss of territory** – people can grow to be safe in a particular environment – they know the rules and gain comfort from them,
- **Reduced expectations** – change can mean the visualised career path suddenly disappearing,
- **Loss of meaning and purpose** – just when the person was confident they knew their place and contribution to the organisation, they have to re-establish themselves.
People faced with change tend to go through similar developmental stages. People experience differing levels of intensity according to their internal capacity to deal with change, the felt effect of the change and the level of support around them:

- **Denial** – ‘They won’t get away with it, it’s just a flash in the pan’,
- **Defence** – ‘The way things are working is okay, we don’t need to change’,
- **Discarding** – ‘I quite like this way of doing things, it’s safer than the old way’,
- **Adaptation** – ‘I want to take up the offer to do some additional training in this area’,
- **Internalisation** – ‘It feels like we’ve been doing it this way for years’.

People can be assisted to work through change by having the fact of loss of self-esteem recognised, and then engaging them in things that will establish it again. These include:

- Access to information that is clear and well understood,
- Having the opportunity to develop new skills,
- Gaining support and encouragement,
- Gaining understanding and empathy,
- Having valued skills recognised,
- Being encouraged to see future benefits,
- Not being over-organised so that innovation can be encouraged,
- Constant and consistent communication,
- Being provided with feedback,
- Being rewarded and involved at an early stage.

**Proposing change**

Your advocacy activity will inevitably propose change, however small. By taking note of the observations listed above, you may realise the potential effects that your proposal can have on people and the organisation as a whole. This does not mean shying away from your actions, but appreciating the processes that may need to go on to bring your expectations of change to fruition.

Change needs to be understood in terms of power, authority and influence. Your proposal, in the first instance, will be more potent if it has the authority of a well-structured, logical and rational position. This is the preferred order of things in a rationalist society. It will additionally benefit from the weight of support of credible and influential people and organisations. Such is the nature of politics.

Exchanging a change proposal between people is usually straightforward. The skills of personal communication are useful here. (Also see 1.6: Interpersonal communication.) The initial requirement is being clear about, and articulating well, what change you are seeking. This planning approach is critical to any change proposition.
Proposing changes to organisations is far more complex. Even small changes seem to create chaos for organisations. The multitude of people involved may each have their own, often legitimate, reasons, for objecting to the proposal. The routine of the organisation may be centred on the very thing that is proposed to be changed. Alteration is seen as upheaval. The problem with organisational change is that it is often required for strategic reasons – the immediate or long-term positioning of the organisation; ensuring its continued relevance; being responsive to its users’ changing needs. These strategic requirements are not always apparent to the staff of the organisation, particularly where there is no culture of participation.

Your change requirements may be more successful if you account for, and engage in, existing power structures. There is little point in proposing change to people who cannot make or influence decisions, unless it is to alter their own immediate practice. Finding the right level of influence does not necessarily mean ‘going to the top’. The ‘top’ may be too busy or disinterested at the time. It also does not necessarily exclude talking up your position with others who may later become influential. Using existing power structures may incorporate:

- **Identifying who has the most interest and empathy.** This may be where a ground swell of support comes from – people ‘talking up’ an idea in an organisation can be very potent for its subsequent adoption.

- **Finding out who makes the sort of decisions you are concerned with.** Decisions are made throughout an organisation according to who has authority. Avoid going ‘over people’s heads’ unless you really have to. Avoid leaving your proposal with somebody too low on the ladder.

- **Identifying who, in addition, influences these decisions.** Decision makers often gather advisors around them. Their view of your proposal is important.

- **Finding out where and how the decisions are made.** You may want to get on to that committee or working group.

- **Embedding your proposal into the decision-making process** rather than relying on a single person. People can change jobs quickly.

- **Inevitably, making sure that your proposal is supported** at the top level.

- **Determining what you can offer.** Think about what you can do to provide support to them in implementing your proposal. Provide options upfront so that decision making is made easier.
Implementing change

Having had your proposal adopted, you may be a relatively passive observer of the change process; you may yourself be affected by it; you may be contributing to its management. A number of points are worth bearing in mind:

- Change is rarely rapid and seeing the benefits can take much longer. There is a pace of change at which organisations operate best. This is to do with the rate of absorption of change with least detriment to the organisation’s functions.
- Longer, careful planning leads to quicker implementation, early success and faster adoption.
- Original concepts may be modified during the change process, particularly where innovation is supported. Be prepared to see your original ideas altered, hopefully for the good. Monitor progress to ensure that the principles are upheld rather than the detail of how to get there.

Contribute where you can or where your responsibilities demand by:

- **Being clear about the strategy for change** – provide leadership and direction, predict and prepare for the new structures and outcomes,
- **Being a role model** – don’t be the one who is resistant to change if things are not turning out exactly as you wanted them to,
- **Ensuring and insisting on open, effective communication** – use meetings, newsletters, encourage casual conversation, have an open door policy,
- **Encouraging innovation,**
- **Providing training and support,**
- **Letting people hold on** to what is meaningful and valuable in their work that contributes to the new order.

References


Despite the positive rhetoric, consumers and carers continue to meet all manner of resistance to their participation with service providers in the mental health sector. Some of the indicators to the things that may contribute to this resistance are outlined here. Knowing about these indicators may assist in modifying your process of advocacy to overcome the barriers.

The relationship between service providers and consumers and carers is underpinned by an imbalance in power. It is this inequality that drives much of the need for advocacy. Consumer and carer participation challenges service providers in many ways. There is a platform of views among consumers, carers and service providers about these challenges that are partial fact and partial myth. Knowing which is fact, which is myth and who holds these views is not simple.

**Facts and myths about consumer and carer participation**

- Service providers see participation as a threat and challenge and are not inclined to give up control over services and decision making.
- The threat to service providers is in their perception that, despite years of training and experience, providing consumers and carers with the process to contribute means they have failed.
- If consumers and carers participate to the fullest extent, service providers may become redundant.
The growing influence of consumers and carers could undermine the very structures upon which professional health workers gain their credibility.

Service providers lack confidence in consumer and carer ability to participate. They are not service providers; they don’t understand the way things work; they are disabled.

Consumers and carers are only interested in good quality services. They are not concerned about management issues.

Consumers and carers are too fatigued, stressed and distracted to participate.

Consumers, in particular, lack motivation; they might not have the required literacy skills; they have travel difficulties.

Consumers and carers lack familiarity with committee procedures and organisational structures.

Consumer participation is observed to come from those who are prominent, who don’t have ‘real’ illnesses and disabilities and don’t represent ‘grass roots’ interests.

Consumers and carers have been actively participating at all levels for many years. Their illnesses, disabilities, and intellect have not proven impediments to meaningful and valued participation.

Facts and myths about service providers

Service providers have different interests from those of consumers and carers.

Service providers carry strong emotions and stress associated with their work including anger, hurt, cynicism, powerlessness, frustration, anxiety and guilt.

Service providers operate in a paradox. On the one hand they want to see the viewpoint of the other and strive for enhanced consumer and carer feedback. On the other they are driven by systemic pressures and expectations which constantly and systematically require them to do the opposite.

Service providers grapple with contradictory roles.

Service providers can confuse people with ‘patients’ and patients are not allowed to be burdened by telling them how you feel about something. This may be considered unprofessional.

It is hard to talk about one’s doubts when you are absorbed in the practice that supports ‘deciding for’ rather than ‘questioning about’.

Service providers are disempowered within their own service structure. The professionalisation of providers somehow forbids them to talk about the things they most want to discuss and which are important to consumers and carers.

Despite their personal beliefs, service providers somehow feel compelled to act in certain ways within their own service structure.

Consumer participation is at the very root of recovery within a service provider context.
Enabling strategies

There are so many assumptions asserted, half-truths told, generalisations made, that finding out what is real seems impossible. Increased, meaningful participation needs to address these issues, not through exposure, challenge and confrontation but through addressing each situation on its own merits. In undertaking advocacy activity, you may want to consider the following as ways of opening doors to participation:

- Adopt an informed approach to advocacy even when forced to take more active approaches like demonstrating or campaigning.
- Be clear about what you want from service providers. Be realistic about what is possible.
- Avoid blaming service providers. Frequently they also feel powerless. They may be victims of a poor system. Avoid being judgemental while, at the same time, not taking responsibility for ‘looking after’ them.
- Encourage service providers to pursue their own empowerment within ‘the system’.
- Where possible and appropriate, engage in dialogue with providers. Demonstrate your ‘humaness’ and not their predetermined perception of your inabilities. Provide permission for broad-ranging dialogue through your own preparedness to be open.
- Demonstrate your worth through reliability, flexibility, empathy and enthusiasm.
- Remain aware of the challenges faced by service providers and look for opportunities to engage the issues. Remember though, that insensitivity can have an adverse effect.
- Develop joint ventures in service quality improvement.
- Create networks with industrial and professional bodies.
- Invite service providers to your meetings.
- Treat every participation event as an opportunity to demonstrate worth.
- Stay in touch with ‘grass roots’ experiences through personal reflection and through involvement with consumer and carer groups.
- Be sensitive to your own and other people’s stigmatising language.
- Become involved in your own education and training for participation.
- Become involved yourself in the training of service providers.
- Talk from your own experience.
- Consider participation to be about offering to help services improve their practice.
- Strive for partnership.

References

Social Care Research Findings (1997) User Involvement in the Control of Voluntary Organisations, Joseph Rowntree Foundation

Victorian Mental Illness Awareness Council (1997) Developing Effective Consumer Participation in Mental Health Services, VMIAC, Melbourne


Wadsworth Y (1997) Dialogue Across Distance – Between Users and Staff of Acute Psychiatric Hospital Services, Unpublished paper presented at University of Southern California
2.7 Keeping the momentum going

While it is a challenge to become involved in advocacy activities as an individual or as part of a group, it is perhaps even more challenging to keep the original enthusiasm and momentum going indefinitely. Many groups start off, but only few survive and continue to grow. This section focuses on skills and strategies to maintain the momentum in groups and to generally apply to the individual.

Staying motivated

One of the best ways to keep the momentum going is to make sure that group members are obtaining satisfaction from their involvement in the group and its activities. People may initially join groups for a lot of reasons, but people stay with groups because they get satisfaction and enjoyment. While the primary purpose of a group may be to conduct advocacy, if other pleasant and enjoyable activities are not present, people may feel they are not achieving anything. They may feel that things aren’t changing quickly enough, become frustrated and leave the group.

People belonging to most community groups offer their time and work voluntarily, so there need to be some pretty good reasons for sticking around. Some of these motivating factors may be:

- Satisfaction from ‘being involved’,
- Enjoyment from being with like-minded people,
- Pride in having made a real contribution to the wellbeing of people with a mental illness and people who care for them,
- Doing work that is valued by others,
- A sense of ‘belonging’.

Group leaders, in fact all group members, need to constantly search for new ways to make sure all the motivating factors above are being addressed. Some ideas for addressing these can include:

- Making sure there is a real purpose behind the group, its meetings and its activities,
- Making sure all members feel they are included in all activities and making a valid contribution,
- Providing an opportunity for members to interact socially and informally,
- Having a way to handle conflicts when they arise (also see 1.12: Conflict resolution/mediation/complaints),
- Having a competent chairperson (and/or facilitator) who can provide direction for the group in both its activities and members’ needs.

Members of groups feel valued when they are remembered. A nice touch is to keep note of all members’ birthdays and have a small celebration. If a member is in hospital or unwell, organise visits or at least send a card.
Review and evaluate the group’s progress

Every six months, it’s good to see just how far the group has come along to obtain a sense of achievement. In a new group there may not be many, or any, successes in the issues that the group is involved in, but there will be many achievements in establishing the group and all the processes involved in this. Celebrate these successes. The following issues can be listed and discussed at the review:

- What are our achievements to date?
- Are members happy with the way the group is operating?
- Is the group on track with its operational plan?
- Is the group effective?
- What are the barriers preventing effectiveness?
- Are there new goals for the group?

Keep things in perspective

In carrying out self advocacy activities, it’s very easy to think that nothing much is improving. While people want to see visible results from the work they’re putting in, positive change often takes a long time to occur. This is especially so in relation to community attitudes and cultures of large organisations. It is a good idea to occasionally sit back and have a look at what has been achieved generally in the mental health area in the last five, ten or twenty years. Groups may want to do this regularly – perhaps every six months or so – as a strategy to maintain momentum and retain morale.

Acknowledging the reality

The reality of working in mental health advocacy and community development is that there is a lot of work to be done by a few people, and there are many obstacles in the way. Sure there are many rewards as well but, unless the reality is acknowledged, the rewards may not seem significant.

The author, Bryce Courtenay, in his book A Recipe for Dreaming says, ‘Dream the impossible dream and start walking towards it’. Then he mentions that on the way to the dream, ‘you’ll be beaten up, chewed, spat out, mauled, ripped apart, given up for lost’. This is called ‘experience’. But then, ‘one bright, sunny morning you’ll discover that the wild and unknown way you took is carpeted with moss and strewn with tiny flowers’.

The reality is also that all people make mistakes except those who don’t do anything. Very little is achieved without some risk-taking, and with risk-taking comes mistakes. All group members need to be encouraged to take risks, allowed to make mistakes and to learn from their mistakes.
Debriefing

Group members need regular opportunities for discussing issues they have been involved in and matters that are concerning them. This can be carried out formally (for example, by having a formal debriefing following an unsuccessful advocacy intervention), or informally (such as discussing some personal problem a group member may have over a drink and burger at a barbecue). If group members have to deal with a lot of these issues on their own, then the momentum of the group will decrease. (Also see 2.1: Briefing and debriefing.)

Achieving and celebrating success

Perhaps the best way to keep momentum going is to achieve success. The key to achieving success for a new group is to start off small. If the group immediately attempts to change the attitudes of the staff in the large psychiatric hospital, they will achieve little success in the short term (over years projects try to do this with little success). The group may see their lack of success as failure, with resulting feelings of despair. However, if the group sets its first objectives as locating a place to hold group meetings and gatherings, or as holding a public forum, it will find success.

Success, no matter how small, brings encouragement and hope. By starting off with one goal and seeing that through to its conclusion, a group can maximise its chance of success. As the group develops and increases its membership and structure, it may gradually take on bigger challenges and more than one at a time. Keep in mind that, if successes start to drop off, it’s time for the group to re-evaluate its activities.

Perhaps above all to keep momentum going, groups need to belong to its members, and members need to belong to the group. When members feel that they ‘are’ the group and derive a sense of value, belonging and fulfilment, then momentum has every chance of growing. Celebrate successes, even the small ones.

References

Courtenay B (1994) *A Recipe for Dreaming*, Heinemann Australia, Port Melbourne
There are two types of budget that are important in advocacy – your own and your organisation’s. Your own budget is important as a part of looking after yourself and enhancing your capacity to maintain your advocacy effort. Where your advocacy activity is associated with the management of a funded project or an organisation, you have responsibilities to ensure economic viability.

Managing a budget means planning the way you spend money so that expenditure does not exceed the amount of money you have. The budget of each person and each organisation will be different.

It is easier to manage a budget when your income doesn’t alter from period to period. If your income does fluctuate, you should consider creating a budget around a minimum income and put money aside in the good times for when the difficult times come. Budgets can be designed around the period of the income, say, weekly or monthly. Never learn to rely on income that is not very consistent. Don’t be tempted to spend a sudden influx of money unless you really don’t need it.
For people on a low income, money management is always a problem. Organisation of money is one way of reducing the problem. The other is to be able to live cheaply and still participate. This requires a little extra thought and planning.

Ideas from consumers include:

- Shopping around for the best deal,
- Cooking meals rather than buying take-away,
- Taking a packed lunch and drink – not buying it,
- Using available resources – opportunity shops, libraries,
- Accessing advocacy resources through organisations,
- Negotiating taxi vouchers and out-of-pocket reimbursement as a representative of a group or organisation.

To organise your personal budget, sort out those outgoings (expenses) that are regular, like rent, and those that can vary, like clothing. Be honest with yourself. Some payments will be periodic, perhaps even once a year, and your budget needs to accommodate them. Multiply everything to its annual amount and divide by the budget period, say, by 52 for a weekly budget.

You may want to use the worksheet on page 107 to sort out your personal budget.

The worksheet on page 108 is typical of an organisation budget. You may want to use this if you are making a submission for some funding, or if you have just started up a funded group or organisation. If you are making a funding submission, the worksheet on page 109 enables you to list the additional one-off items that may be required.
Managing Your Personal Budget – Sample

How often do you receive an income. For example, is it weekly, fortnightly, monthly? Use this period for calculating your budget.

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</tbody>
</table>
### Capital Equipment Requirements – Sample

<table>
<thead>
<tr>
<th>Item</th>
<th>Quantity</th>
<th>Cost per/unit ($)</th>
<th>Total cost ($)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Computer</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Computer Software</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Fax Machine</td>
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<td></td>
<td></td>
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<tr>
<td>Motor Vehicle</td>
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<tr>
<td>Modem</td>
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<td></td>
<td></td>
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<tr>
<td>Office Furniture</td>
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<tr>
<td>- Desk</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>- Chair</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>- Filing Cabinet</td>
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<td></td>
<td></td>
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<tr>
<td>- Bookcase</td>
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<td></td>
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<tr>
<td>Photocopier</td>
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<td>Printer</td>
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<tr>
<td>Shredder</td>
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<td>Telephone</td>
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<td>- Fixed</td>
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<td>- Mobile</td>
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<td>- Pager</td>
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<tr>
<td><strong>Total</strong></td>
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</tbody>
</table>
Managing a contact list

Whether for your personal or organisational networking activities, or for managing links in a particular project, you may want to maintain a contact list. A sample form, which may be useful for keeping a manual contact list, is shown on the next page. Use a pencil for the boxed items, so that you can erase and overwrite with new information.

Maintaining the list

If you are keeping your contact list manually, you will need to keep the separate pages in order. Use a ring-binder to keep them in. You can modify this form, put each entry on a card and keep the cards in a box. Using an alphabetical ring-binder insert or ‘tabs’ in the card box can be useful for large numbers of contacts. In any event, keeping them in alphabetical order by name makes locating them easier.

Add new forms as you fill them out. Regularly (say, every week) review each form and make a note of the actions to be completed during the period, and check that the next meeting is organised. During the review, throw out those that are no longer current, or keep them in a separate place for future reference.

Computerised contact lists

If you have your own computer, maintaining a contact list is quite straightforward. There are many software applications around for managing contact lists; some of them available free as public domain software.

Depending on the software, you can manage a contact list and use it to create an ongoing diary for yourself, sort out contact details by characteristic (such as type of organisation) and to generate mailing labels.
<table>
<thead>
<tr>
<th>Name</th>
<th>Organisation</th>
<th>Address</th>
<th>Postcode</th>
<th>Telephone</th>
<th>Home</th>
<th>Other</th>
<th>Fax</th>
<th>Home</th>
<th>Other</th>
<th>E-mail</th>
</tr>
</thead>
</table>

**Notes about the person** (major issues, interests, skills, etc)

....................................................................................................................................
....................................................................................................................................
....................................................................................................................................
....................................................................................................................................

**Actions agreed and completion dates** (what each agreed to do and by when)

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**Next planned contact** (details of further agreed contact or date on which to make further contact)

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Evaluation may be seen as a branch of research that has a particular focus on the value of events. ‘How good is it, do people like it, does it achieve what it is meant to?’ Evaluation is about how people value something so, in itself, evaluation is political. As commonly said: ‘What you see depends on where you sit’. People will value something according to their own frame of reference, their relationship to it, their investment in it. Measuring and reporting on values needs to take account of the relationship between values and power.

Research and evaluation are often steeped in mystery. Undoubtedly, some aspects of research and evaluation can be highly complex. However, the fundamentals of evaluation are, in fact, second nature to everybody.

During people’s daily lives they constantly undertake evaluation. People evaluate whether the coffee is too hot, whether it is safe to cross the road, the benefits of taking a bus or walking. More complex evaluation is merely an extension of what people do naturally. It incorporates a more formal approach and use of additional skills.
In everyday evaluation, like deciding whether to walk or take the bus, people make loose judgements about whether they want to spend the money on the fare or something else, whether they could do with the exercise, or whether they have the time to walk and, usually, the decision has no major consequences. This approach is not acceptable for more complex decisions where the outcome may, for instance, mean a change in service provision or loss of funding for an organisation.

Evaluation takes what people do naturally and builds on it. It moves beyond their intuitive sense of what is good or bad, better or worse by introducing increased rigour into the process. The results of evaluation enable people to have increased confidence to pursue a particular course of action. Evaluation in mental health services almost always supports decision making about things that affect people. While evaluation is not a difficult thing for consumers and carers to do at a fundamental level, more complex evaluation requires increased skills. The implications of the way results may be used suggest that evaluation needs to be undertaken seriously.

This section considers some aspects of basic evaluation and overviews a few of the more common forms of complex evaluation.

**Reflection**

The key skill used in basic self-evaluation is reflection. Evaluation is a means for learning by experience. With most activities you evaluate the situation and come to a decision often without realising you have done it. You may scald yourself with the coffee before realising it is too hot, but are unlikely to take another sip until it cools. How often, though, do people put such experiences behind them without a further thought and go on to make the same mistake again? They usually become quickly aware of the need to avoid hot coffee, but the learning to be drawn out of more subtle events in life can easily be overlooked.

Reflecting on your actions is a growth experience. It provides for improvement in skills and knowledge when things do not go so well. It creates self-worth when things do go well.

Advocacy activity incorporates a number of characteristics that are amenable to reflection:

- **Planning** – Did you prepare and plan well? Did your planning contribute to the outcomes of the activity?
- **Process** – Are you satisfied with the way you went about it? What would you do differently next time?
- **Outcomes** – What do you want to achieve? How will you know that you have been successful? Was it worth doing? Did it achieve what you expected?
Reflection does not need to be about deep soul-searching. It is certainly not about self-blame. Reflection is far more a self-affirming activity. It enables the elements of an activity to be broken down and seen for what they are. Every advocacy activity will be successful. You may not have achieved exactly what you wanted, but your contribution to altering an attitude or introducing a new idea will be setting seeds for longer term change.

Reflection is something worth practising; taking the time out to consider your own actions and even those of others. You may want to do this on your own or with other people. You might expect those you are reflecting with to be supportive and positive and to contribute fresh ways of viewing the situation.

Feedback
Gaining some fairly immediate statements about an event, or getting feedback, can come in more or less formal ways. You may find people giving you unsolicited feedback about the process you used or the results you achieved. You might take this information into account as part of your own personal reflection.

You may have people giving you informal feedback about an event because you ask them to ‘keep an eye on things.’

If you are in a position to receive frequent feedback, it may be useful to purchase a memo book to write down incidental comments and bits and pieces of feedback that come in unsolicited and unusual ways. An example of unusual and unsolicited feedback occurs when one consumer is asked to stay for lunch after she has given a talk to a group of people. As she sits at the table making polite conversation she is passed a note written on the back of a paper serviette. It says simply, ‘That was fantastic. Thank you so much’.

Feedback is a relatively informal type of evaluation that provides information about something without undertaking much design for its collection. Using feedback is an important part of finding out and can lead to identifying areas for more formal evaluation.

Formal feedback is usually written. It is important that this information is filed systematically when its wider usefulness is recognised.

Evaluation
Why evaluate?
Basic processes of evaluation – planning, delivering, reflecting and modifying – are useful to keep your advocacy activities on track. In moving from basic self-reflection to more complex evaluation, a number of techniques can be considered, from occasional informal feedback to more formal methods like interviewing or survey. Any of these methods will, in their own way, increase your knowledge and enable better decisions to be made.
However, there is also a compelling political motive for undertaking evaluation. Advocacy activity involves putting forward a position in the expectation of creating some change in a climate where the balance of power is not equal. Power is often experienced and accepted in relation to knowledge and information. Those that are seen as knowledgeable are more likely to have their values ‘accepted’ by those with power. **Often the most powerful do not have to ‘prove’ their knowledge. Their status somehow gives them unquestionable authority.** For those in less powerful positions, demonstration of the value of things is a fundamental requirement for change.

Evaluation, whether informal or formal, is an invaluable aid to anyone or any group trying to gain more secure funding or a further grant to continue their educational work.

**Engaging in evaluation**

Consumers and carers become involved in evaluation in a number of ways including:

- As the subject of the evaluation – did this clinical intervention have a good result?
- As the population of the evaluation – how well does this service meet the needs of these people?
- As evaluators – how do their peers want this issue to be represented?
- As service providers – do the carers who attend this group benefit from it?

As the subject of evaluation, consumers and carers can become cynical of the benefits of evaluation. Another questionnaire to fill in, another interview to attend, another doctor to see. Cynicism tends to be derived from not hearing about the results or of not feeling a genuine part of the decision-making process. Gaining increased understanding of evaluation can assist you in:

- Your decisions about giving informed consent,
- Choosing whether or not to participate as a subject in evaluation,
- Providing advice about evaluation design,
- Undertaking evaluation yourself.

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*When it’s suggested to Adam that he be part of a trial for a new drug, he is able to discuss with his doctor how the evaluation of the drug is to take place. He discusses the methods to be used; what is already known about the drug; what effects the drug is meant to have; how they measure whether these or other effects occur. When he is satisfied with the answers he agrees to give his consent, provided he is sent the results of the research.*
A social work student approaches two carers she knows to interview them about the needs of carers and how her service can most appropriately respond. As they question her about her method, they realise that only they and two other carers are being interviewed. All four care for elderly people and yet the service is established to provide support to people of all adult ages. They consider themselves unrepresentative of the range of carer needs that the service might discuss. On this basis the two carers request that the student modify her method before approaching them again.

Martin is employed as a consumer consultant and, as such, has a responsibility to ensure that area mental health services are made aware of consumer interests at a number of levels. One of the housing and support services is about to undergo an agreed change of direction. Martin discusses his concern that, while supporting the change at one level, he wants to ensure that the outcomes will be no worse or, indeed, that they will improve. He thinks up some useful questions to systematically ask consumers before and after the change.

Undertaking evaluation

Regardless of how complex your evaluation is going to be, the following steps may be taken into account:

Consider what it is you want to know

The process of finding out is time-consuming and sometimes difficult. It is unnecessary to evaluate everything. Decide which are the most important things and concentrate your effort on them. Ask yourself, ‘What is it I/we really want to know about/understand better?’.

Be clear about the questions you want the evaluation to answer. A lot of effort can go into answering a question that is not relevant to the issue at hand.
A group of consumers believe that a mental health service is not providing sufficient support for them because of the large number of people serviced. They therefore consider it an inadequate service. The service itself is bound by a funding agreement to service this number of people. Is the group’s evaluation question, ‘Does this service meet its obligated access requirements?’, or is the question, ‘Does this service provide quality support for participants?’

The quality issue is relevant to them but not, seemingly, to the service. The relevance of the evaluation question depends upon who is asking the question. Counting heads will not satisfy the group’s concern.

The consumers may determine that the more relevant evaluation question is, ‘Is it the funding framework to which the service is subject or the way the service is organised that provides for an inadequate level of support to participants?’

Be clear about why you want to know
Every piece of information collected will require analysis or collating in some way. Sometimes people jump into information gathering, ‘While we are collecting that, we might ask for that as well.’ Seriously ask yourself why you want this information and whether it is relevant to the evaluation question.

Can you do anything with the information? If somebody has asked you to do the evaluation, you might reasonably expect it is for good purpose. However, it is worth checking. Ask yourself, or the other person, ‘What is the purpose of this evaluation? If I knew the answer to this evaluation question, how could the information actually be used?’ If you cannot define the purpose of doing the evaluation or how the results will be put to good use, you might want to reconsider why you are doing it.

Decide who the audience for the results is. This is often called a ‘stakeholder’ analysis. Simply put, the kinds of issues that advocacy activity is dealing with will usually affect lots of people. If your evaluation is to demonstrate a point, a range of people may be interested in the result. Some will want an honest appraisal; others may prefer not to know. It may be possible to tailor your evaluation question to take best advantage of the various interests that people have. You might want to actively involve stakeholders in the project. Maybe ask them to be a steering committee for you.

Find out what is already known
What can you draw from your own experiences? Is there something written about the issue? Has someone undertaken a similar evaluation? Is the matter already being dealt with in some other way?
Decide how you will proceed

There are many ways that evaluations are undertaken. The number of different models that are described can be very confusing. It’s best to keep it simple. This is all that is required for most advocacy activity. Remember, there is no perfect evaluation design.

If your evaluation question is clear, the methods you use will be more obvious. Ask yourself, ‘What do I want to find out?’ The answer to the question should tell you how best to do the evaluation.

Some evaluation methods will tell you if people like something or not; others will tell you why they hold that opinion. Be clear about what you want to know. For instance, if a funding body wants to know how many participants are satisfied with a service, you might undertake a survey. If the question is about what makes them satisfied or dissatisfied, you might undertake interviews.

You may consider a number of alternative methods and decide to adopt a particular one, or use a number at the same time. Sometimes using more than one method can reduce errors in the findings. This approach is sometimes called ‘triangulation’.

### Ways of finding out

Evaluation is essentially about comparing two or more things and assessing the differences. You might:

- Compare what is happening now with the way people said it was meant to happen,
- Compare what is happening with some agreed notion of how it should be happening,
- How it is in one place compared to another,
- How it is at one time compared to another time.

Having decided on what you are comparing, you can work out the best ways to gain the information. These may be:

- Counting the number of occasions that something happens,
- Recording people’s views through informal conversations or formal interview,
- Checking records to see if they show something is happening,
- Observing a situation to see if what is meant to happen actually does,
- Doing some or all of these together.

Many people see evaluation being about undertaking surveys. Formal surveys should not be the method of first choice in advocacy activity. They are difficult to do well, time-consuming, require a great deal of recording and analysis, and are not necessarily any better than other ways of finding out, particularly at a basic level. Consider other methods like group discussions, a range of informal interviews or being very observant. Keep good records of these events; use verbatim quotes; describe real events. These are very potent methods of evaluation and reporting in advocacy.
Decide who or what will be your sources of information
Decide where you will look. Do you need to gain permission to access some records? Do you need to go to a library? What can you get from the Internet? Will you want information directly from other people? Will it be alright for you to just watch what goes on?

Consider how much information you will collect. Do you need to get everything on a subject or just the most critical things? How many people do you need to talk to (sample size)? Who do you need to talk to? How many records do you need to see? How long will you continue to observe the number of times something happens?

**Sampling**

Sampling means choosing a particular number of people from all the people that you could have as participants in your evaluation. Your sample may be all the people, if this is a manageable number, or a selection from all the people. The reason for choosing a sample rather than all the people is to reduce the amount of work required to achieve the same results. ‘Sample sizes may vary depending on what you want to know, the purpose of the inquiry, what’s at stake, what will be useful, what will have credibility, and what can be done with available time and resources.’ The sample group may be only one person. It can be sufficient to purposefully select an ‘information-rich case’ to inform particular issues through, say, a case study.

Sampling has its roots in experimental research and has a sound rationale. It is also used to disarm and discredit people who are undertaking advocacy activity. ‘What you are telling me is the opinion of a small number of people and isn’t what most people think about it.’ For these critics, strength of argument comes, in part, from demonstrating that enough people hold the same view.

For the most complex types of evaluation, there are some strict rules about sampling. However, for most consumer and carer advocacy-based evaluation, it is usually enough to be satisfied that a sufficiently representative group has participated in the evaluation to cover the range of possible answers. Most criticisms can be met by maintaining a reasonable degree of rigour in your evaluation.
Consider rigour

Rigour is a word that is used in evaluation to describe thoroughness and professionalism.

Some people conduct their evaluation in a way that might be called ‘positivist’. The researcher assumes that certain facts exist and can be discovered. There are important guidelines about rigour that must be followed if the research results are to be considered well-founded. Most biomedical research fits into this category. Some social scientists also adopt a positivist approach to research. They believe that if their work is done ‘objectively’ they will discover certain facts or truths.

Some basic questions used for checking the rigour of your evaluation methods include:

- Have you included enough people to constitute a big enough sample?
- Was this selection of participants done according to one of the accepted scientific methods?
- Was the evaluation undertaken systematically?
- Did you ask each person exactly the same question using exactly the same words?
- Did you record everything accurately?
- Did you take all the information into account in forming your conclusions?

There are methods of thorough and professional evaluation and research that do not attempt to be ‘objective’. Researchers who adopt this approach do not presuppose the existence of ‘social facts’. They argue that people see and experience things in the world in different ways and construct their meanings accordingly. Collecting stories, personal observations, conversations, may fall into this category of research.

Research methods that do not seek to ‘prove’ the existence of social facts are not necessarily less rigorous. Here, rigour lies in the way that such research is conducted. Rigorous practice can include systematic record-keeping of incidental comments and daily activities. Collection of data might involve investing in a bound memo book or diary rather than in a computer program.

There is a common misconception that ‘scientific counting’ equals rigour equals ethical research and that, therefore, watching and listening and working in different ways equals non-rigour equals less ethical research. This is not true! The difference between the two ways of learning about society has more to do with the ideas that define the two methods than it does about rigour. Researchers working in either way can be more or less rigorous.
Consider ethics

‘The evaluator’s scientific observation is some person’s real-life experience. Respect for the latter must precede respect for the former’

from Halcolm’s Evaluation Laws

Ethics are the ‘rules’ that guide expected conduct. Some actions in evaluation are considered unethical. These include:

● Harming people,
● Having people participate without their full knowledge and permission,
● Invasion of privacy,
● Not maintaining confidentiality,
● Misrepresenting the facts of the results.

It is the responsibility of all people undertaking evaluation to maintain the highest possible standards. It may be that no particular written standards are available to you, in which case discussion amongst a group of people about issues of concern may assist in resolving them.

It is a fundamental ethical principle that no person can be used as a research subject without giving his/her consent.

Consumers and carers have found that a person who does not really wish to be involved in a project sometimes gives consent. Sometimes consumers are afraid to refuse to participate, especially when they are in hospital. They fear that they may not be able to get out if they are not obliging. Consumers are often afraid of being punished. Consumers also report that they want to please their doctors. Sometimes this means agreeing to anything.

If genuine consent is to be sought then these fears and concerns need to be addressed. Consumers and carers need to know they have the right to refuse consent. All subjects should feel free to withdraw from a project at any time without fear of repercussions.

Full and clear information, such as the nature of the research, who is conducting it, who is funding it, the publication of results, anonymity, should be given to those invited to participate.

Consumers and carers intending to be involved in ethical consumer or carer perspective evaluation projects need to remember the importance of treating all participants with respect. This respect might involve:

● Getting other consumers and/or carers to help design the research tools (for example, questions, reviewing processes) in the first place,
● Sending a copy of your interview notes to the person you interviewed and asking if the notes accurately represent what he/she said,
● Keeping every participant up-to-date on how the project is going – if there are delays let everyone know,
● Doing exactly what you have told people you are going to do – if this means putting notes, tapes and other materials in a locked filing cabinet, then make sure it’s locked – if this means erasing tapes, then make sure they are erased,
● Being careful with information that has been collected – file it efficiently. Make sure that anything that is no longer needed is shredded or erased – don’t reuse or recycle paper with someone’s personal story on the back of it.

Always disguise the name of the person being interviewed on a tape or in a transcript. You must be sure that you have done everything you can to protect the privacy of the person.

If a person is taped, the researcher needs to discuss with him/her whether the tape will be transcribed (typed word for word) or used to make notes. Either way, the notes or transcription need to go back to the participant with the question, ‘Is this what you meant to say? Change anything that you are not happy with.’

If more than one person is featured on a tape, then each individual must be consulted.

If you are attempting to quote or paraphrase someone in conducting this kind of ‘personal’ research you are ethically required to ask the person who is being quoted, ‘Have I got this right?’

It is particularly important that you take notice of any comments, disagreements or suggestions provided by participants. It is not enough just to ask for feedback and revision – you must be prepared to make changes even if this means delaying the completion of your work.

Often a researcher is under pressure to meet a ‘deadline’. But anyone doing consumer or carer perspective research must balance concerns about efficiency and performance against the importance of respectful research processes. Consumer and carer researchers may need to take responsibility to educate governments and other funding bodies about ethical process issues.

Send a copy of the final report (or any printed document such as a conference paper) to each participant. This should occur regardless of the actual research methodology. Participants are entitled to know how their life stories have been used. Some researchers argue that more than this is necessary and that the consumers/carers who were involved in giving the data need also to be involved in interpreting it.
Create the tools

Some evaluation is fairly informal, say, a discussion to collect descriptions of events. You will need a way of keeping records.

Using observation as a method of evaluation may require you to keep a diary to record what you observe and what it means to you.

Some evaluation may require a more formal approach and some planning. To be clear that the responses you are getting to your inquiry are not tainted by misinterpretation, you may need greater structure. One-to-one interviews will be improved if you write down the questions and then read them to each person. You will also need a way of recording the answers.

You may want to use observation as the method, to observe and create field notes of events. Again, you will need to determine an accurate method of recording your observations.

Another form of inquiry is to provide a questionnaire to people, using the same set of questions, for them to answer by themselves.

Surveying may be undertaken by asking people specific questions, engaging in formal dialogue or by providing people with a survey form.

Each method requires some planning:

● Have you got the resources – your own and others’ time; enough stationery, printing, photocopying, postage costs; any other essentials?
● Do you have the skills to construct a survey form to meet your purposes? Is there someone else that can assist?
● Do you have a way of piloting the survey form to make sure that it will produce the type of responses you expect it to?
● Have you decided how you will make sense of the responses?

Surveys are about answers to questions. How you construct your questions and how you provide for people to answer them is important. Keep surveys simple. People can be very quickly put off a survey if it is too long, too complicated or unclear to them. Reduce the number of questions down to those you really need the answer to. Don’t be tempted to add questions simply because ‘it would be good to know that too.’ If you are planning to embark on surveying, you can use the example on pp 125-126 as a guide. The discipline of organising questions in this way is also useful for interview surveys.

Interview surveys are not always about specific answers to questions. You may want to use the ‘open-ended’ question: one that encourages people to talk freely about a given topic. These types of surveys give rich information about people’s opinions and attitudes. They are also very difficult to accurately record and interpret. Depending upon the type of interview, you may want to create an interview guide. This will be very similar to a ‘questionnaire’, but used by you to remind you of the questions and assist in asking them consistently between people. You may want to use interviewing to gain from people important statements, quotations or to develop a case study as a strong example of a particular issue.
Apply the method

Use as much time as it takes. It always takes longer than you first anticipate, so be prepared. Accept that things get in the way: people won’t be available when you want them; it’s Christmas and everyone has gone away; there’s a transport strike when you have a group meeting arranged. Expect that making sense of the results will take just as long as the time used to undertake the inquiry.

Follow your plan as much as possible to stay organised, but be open to new opportunities. You may discover things in your preliminary inquiry that encourage you to move down a new track.

Sort out the results

Go back to your purpose. What was it that you were making comparisons between?

Make a judgement about the new information in relation to the thing you are evaluating. How does it contribute to your understanding now? How confident are you in asserting a particular position? Are there new actions to take or recommendations to make?

If it is practicable, let the people who contributed to the evaluation know what your findings are. Write a note of thanks and send them a summary or present your findings to them as a group.

Decide whether your findings need to go in a report to someone. Your well-organised evaluation may be sufficient in its own right to persuade someone to act.

References

Patton M Q (1990) Qualitative Evaluation and Research Methods, Sage Publications, California
A survey of users’ opinions about the support group

Thank you for agreeing to participate in this survey. Your privacy will be maintained at all times.

1. What are the three best things about the current group?
   1. 
   2. 
   3. 

2. What is the highest number of carers that should attend the group?
   (Tick only one)
   - Less than 5
   - 5 to 7
   - 8 to 9
   - More than 9

3. Should the group provide support and education?
   - Yes
   - No
   - Don’t know

4. Do you agree or disagree that people should not join a waiting list?
   - Yes
   - No
   - Don’t know

5. Please state your age.

6. What would you do if the group was no longer available to you?

---

Let the first question be the one that people can feel good about

Be clear that the words you use have a common meaning for everyone. The term ‘carer’ has many different meanings.

Make your instructions clear.

Be sure to include all the options in a multiple choice list.

Only address one concept in each question. Avoid using the words ‘or’ and ‘and’ in a question. It means there are two questions or two alternatives in the one question.

Avoid the hypothetical. It provides unreliable results.
7. Do you favour or oppose the groups continuing to meet? (Please comment)

Be very careful not to lead the answer in a particular way. Asking this question is unlikely to receive a negative reply.

Open-ended responses provide rich information but are hard to analyse.

8. Which one of the following statements comes closest to your general reaction to .......... ’?

a ............................................ □

b ............................................ □

c ............................................ □

d ............................................ □

e ............................................ □

Other .................................. □

Please specify

.................................................................................................................................
.................................................................................................................................

A useful safeguard in case you left out a possible response.

It is generally easier to make sense of the responses when the possibilities are restricted.

9. How supportive is the group to you right now? (Place a cross on the line)

Supportive .................................................................Unsupportive

You can ask people to rate on a continuum or on discreet points.

10. How satisfied are you with the level of support provided by the group right now? (Please circle)

1  2  3  4  5

Extremely  Very  Average  Not very  Not at all

11. Have you received enough information on education programs?

Yes □

No □

You may want to mix a closed and open response.

If No, what else do you require? .........................................................................................

1 Patton MQ (1990) Qualitative Evaluation and Research Methods, Sage Publications, California, p184

2 Patton MQ (1990) Qualitative Evaluation and Research Methods, Sage Publications, California, p143
Specific roles, tasks and events provide an important opportunity to advocate. This section of the Kit focuses on a small range of specific skills and strategies; they can be linked with personal, interpersonal and preparatory skills and strategies in other sections of the Kit.

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3.1 Presentation/education

Consumers and carers who decide to participate in educational activities for service providers, students, administrators, media representatives, politicians, other consumers and carers or members of the general public need to develop and polish a number of skills. The information set out below aims to provide a grounding in the most fundamental and important of these skills. In addition, this section includes advice relating to some important ethical issues that arise for carer and consumer educators.

Preparing your message

Who are you speaking for? If you are speaking for yourself, then the preparation of your message is under your own control. Just remember that if you mention other people you need to have their permission (also see 3.2: Telling stories). If you are speaking on behalf of a group or for another person, this involves discussion and negotiation in relation to each of the following points. In either case make sure that you let the audience know what perspective you are coming from.

- **What is your message?** It’s necessary to have a clear idea of what you wish to say. While this may seem basic, it’s worth bearing in mind. Any confusion on your own part will translate into confusion for your ‘audience’.

- **Who are you speaking to?** Who is your ‘audience’? A message is always intended for someone and your preparation needs to take this into account. How you ‘pitch’ your message depends on who you are addressing. For example, in speaking to a class of fourteen-year-old students about consumer experiences, you may need to explain many concepts and terms that are readily understood by an audience of carers, service providers and other consumers.

- **What is the purpose of your message?** Do you wish to persuade, to provoke, to convey simple facts, to ask for opinions, to gain support or something else?

Getting your message across

Decide what method of delivery is most appropriate for you, for the nature of the message and for the intended audience – for example, a letter, a written submission of some kind, a formal spoken presentation, an informal discussion with one or more people, an interactive workshop, a petition, a demonstration. Different methods require different skills on the part of the presenter or organiser.

Try not to use too much jargon (technical or professional slang which may be unfamiliar to many people). If you do use terms which may be unfamiliar to the audience, explain their meanings briefly and simply.
If you are giving a talk, it may be useful to use diagrams, cartoons or headings to illustrate or simplify your main points. Overhead transparencies are quite simple to prepare and use (see page 131). Alternatively you can use handouts, but these are less effective in many situations because audience attention is drawn away from the speaker.

If you are writing a letter or making a written submission, it is most useful to have it typed rather than handwritten. This eliminates one source of potential misunderstanding – that is, difficulty in reading the message. If you do write by hand, it needs to be as neat and clear as possible.

Invite questions and feedback from your ‘audience’ (even if this means follow-up letters, phone calls). This way you can clarify your message and correct any misunderstanding.

Use diplomacy: Even when dealing with a sympathetic and/or responsive audience, it is a good idea to include some positive elements within your presentation, especially if the overall message is one of complaint or criticism. For example, if you are complaining about a certain aspect of service delivery, then include some constructive suggestions about how that service delivery could be improved.

Public speaking – some helpful tips

Make sure that you prepare your presentation in plenty of time before the actual event. Last minute preparation will not help your confidence or the clarity of your message.

- Abstract: If you are delivering a conference paper, you need to submit an abstract of your paper to the conference organisers – a short description (50 to 100 words) of your presentation. Details concerning the abstract are usually provided in the ‘Call for Papers’ that is circulated some months before the conference. Your final paper may differ slightly in content and/or focus from your abstract summary.

- Choosing a title: The title can include some reference to the conference theme, you might use humour or you might keep it very simple and straightforward. Try to come up with a ‘catchy’ title.

- Deciding what you will wear: Take into account the weather conditions, the venue, and the image you wish to present to your audience. Most importantly, dress for physical and mental/emotional comfort.

- Practising your presentation: You can practise in front of long-suffering family or friends; in front of a mirror; into a tape recorder. Time these practice sessions: it is important not to go over time in delivering a spoken piece. Your audience may ‘switch off’ if you go on for too long and you risk straying from your main points. Also, if there are other speakers scheduled after you, it is inconsiderate to take time away from them.
Some Specific Activities

3.1 Presentation/education

- **Using notes:** Some people can make very successful presentations without notes of any kind. Most of us require notes. You can use key point cards or more extensive notes – in either case, try not to read your entire ‘speech’ directly from notes. One of the most important ways of getting your message across is to speak to your audience as directly as possible – you can’t do this with your head down, reading.

- **Relating to the audience:** The best way to reach the people in your audience is to look at them. Make eye contact with one or two people in different parts of the room – somewhere there will be someone nodding or smiling. If you can’t make eye contact, look over the heads of the audience (not too high) towards the back of the room. This ploy gives the impression of looking at the people.

  Another important reason for looking up rather than down at notes is that your voice will carry much better.

- **Using a microphone:** In a small venue you will not need a microphone, but in a large auditorium this may be necessary. Try to practice speaking into a microphone if you have not done it before. Remember not to put your mouth too close.

- **Using equipment:** If you are using video, slides or overheads, make sure that the appropriate equipment is ready before your presentation and that you are familiar with how it works. The audience will become restless and, therefore, less receptive, if you spend 10 minutes trying to get the overhead projector working.

  Always have a glass of water handy. Nervousness can give you a very dry mouth.

- **Delivering your presentation:** Do not rush. Talking too fast will make you difficult to understand and will not give people time to think about what they are hearing. Try to vary your tone of voice: a monotonous delivery will send the audience to sleep (especially in the afternoon).

- **Finding a place for your notes:** If you use notes, it’s helpful to have a stand of some kind to rest them on. If you hold them in your hand this can make any shaking more evident, which is not good for your morale.

- **Using hand movements:** Some people wave their hands around when they are talking. If you do this when giving a presentation it can be very distracting for the audience, so try to minimise unnecessary movements. You can use your hands to emphasise important points, but do not use them for ‘punctuation’.

- **Inviting questions from the audience:** If you wish to invite questions from the audience after your talk, then you must allow time for this – another important reason for timing your presentation beforehand.
Getting people to understand you

Some general remarks
One of the most useful ways of improving understanding is to have discussions (dialogues). In workshops and informal group sessions any misunderstanding can be addressed straight away due to the interactive process.

Whatever your message and however you choose to present it, try to emphasise the most important points. In a spoken presentation you can summarise these points at the beginning and at the end of your talk or use overheads or slides. In written presentations, too, summaries of the main points are important. You can use larger or heavier type, double spacing and so on to make these stand out.

A golden rule (For those who like golden rules!)
AIM at addressing three main points in your presentation.

Different people learn in different ways. If you have three main points, it’s a good idea to make them in several different ways. Some examples of different teaching methods are:

● Clearly state the main points and write them on an overhead, chalkboard, whiteboard or slides.

● Tell a short story or anecdote which highlights one or more of the main points – you might decide to use humour in this form of storytelling.

● Use a powerful quotation – write it on the whiteboard for audience members to see when they enter the room. They will often sit there trying to work out the significance of such a quote while waiting for you to start.

● Ask rhetorical questions which encourage the audience to question their own attitudes and values – be careful not to overuse this particular tactic.

The Learning Heads (adapted from Arnold R, 1997)
People are helped to retain information through the different ways they receive it:

<table>
<thead>
<tr>
<th>Hear only</th>
<th>See only</th>
<th>Hear and see</th>
<th>Hear, see and talk</th>
<th>Hear, see, talk and do</th>
</tr>
</thead>
<tbody>
<tr>
<td>20%</td>
<td>30%</td>
<td>50%</td>
<td>70%</td>
<td>90%</td>
</tr>
</tbody>
</table>

Amount retained
Using visual aids

As mentioned above, some individuals find it a great deal easier to understand and remember information if it is presented visually. Showing a film or using posters, photos or slides may be suitable for some types of presentation. However, the visual aids that are most commonly used in spoken presentations are overheads and whiteboards.

Overheads

There are some important things to bear in mind when preparing overheads for use in a presentation.

- Use **dark marker pens** so that your writing and diagrams are easily visible. Avoid using green pens.
- If you use non-permanent markers, the overhead sheet can be cleaned and re-used. However, these pens can easily smudge so try not to touch the actual writing when moving the sheet into position.
- Do not clutter your sheet with too much writing – **stick to the main points**.
- Do not write too close to the edges of the sheet.
- Overheads can also be made by photocopying typed or printed documents and illustrations. These, too, should be kept uncluttered and simple.
- There are two different types of overhead transparency sheets. Only one of these can be used with a photocopier – make sure you have the right one.

![A good overhead...](image)

1. **needs to be clear and simple**
2. **should not contain too much information**
3. **Should be used to emphasise your main points**
4. **Is a very useful presentation tool if used sparingly.**
Whiteboards
Some people find a whiteboard useful for writing up their main points. This gives both speaker and audience a framework to follow. When using whiteboards the following points are important:

- Do not use green whiteboard markers: they are very hard to read.
- Do not use permanent markers!!
- Make sure you have access to the whiteboard duster or cloth before you start – bringing your own materials is probably the best idea.
- If you have been able to write up your main points prior to starting your presentation, ask the first few audience members to arrive whether they are able to read what you have written – you can try moving the whiteboard to give more people a better view. This is also a good way of breaking the ice with your audience and settling your nerves.
- You may like to write a simple ‘Welcome’ message on the whiteboard. This helps to create a positive atmosphere.
- It’s quite difficult to write near the bottom of a whiteboard, so try to start as near to the top as possible if you have several points to make.
- You may find it hard to keep your writing straight across the board. Try to have a practice before your presentation, and keep your lines fairly short.
PowerPoint: the future of visual presentation?

PowerPoint is a computer program that can be used to create a number of sophisticated aids to presentation. PowerPoint can even be used to run an entire presentation via a network of computers.

What PowerPoint allows you to do is to create ‘slides’ on your computer. These slides are the ‘pages’ of your presentation and can include titles, text, charts, drawings, clip art, movies, sound.

How you use the ‘slides’ you create depends on what kind of presentation you are giving. If you are trying to reach an audience whose members are not ‘on line’, there are ways that you can adapt your computer-created ‘slides’ to suit.

● A service bureau can change your PowerPoint ‘slides’ into regular 35 mm slides – these can then be shown using a slide projector.
● PowerPoint ‘slides’ can be printed as transparencies for use with an overhead projector.
● The ‘slides’ can be printed as black and white paper handouts to give to your audience.

References
Telling stories

Storytelling has been a major part of consumer and carer participation in educating service providers and others. People’s stories help to bring theoretical problems to life and can be extremely effective in promoting greater understanding and appreciation of consumer/carer concerns. However, there are a number of important issues around storytelling that must be understood by any consumer or carer who is asked to contribute in this way.

Your own story

Some people find that they are intuitively good at responding to an audience. They have a ‘flair’ for this sort of activity and enjoy storytelling. With experience, they tend to rely less on preparation and more on a genuine enjoyment of telling their story. However, for most people preparation is important.

In some ways telling your own story is easier than telling someone else’s. But it can also be harder. The most difficult aspect of telling your own story in public is that it is about yourself. It is often painful to remember, and sharing personal pain with others is not something that everyone can do.

The first step to telling your story is to make the decision that you can share your pain, your emotions and your experiences with your audience.

- Write down your story. This is a good way to keep the story ‘under control’. Writing about your experiences will help you to decide just how much of yourself you want to make public and to identify what are ‘no go’ areas.
- If you feel too vulnerable telling your story in the first person (‘I had such and such an experience’), then you can choose to tell it in the third person (‘he/she had such and such an experience’). This can be a useful way of reducing the emotional strain attached to personal storytelling. You can decide whether or not to tell the audience this is what you are doing.
- Believe in the value of your story as a way of getting your message across. This happened to you and you are the ‘expert’ about your own experiences.

Part of preparing for a storytelling session is knowing which story to tell – and why.
In *Developing Effective Consumer Participation in Mental Health Services*, the authors talk about the use of parables to emphasise the importance of knowing which story to tell. A parable is a story with a message. The story is told in a way that encourages audience members to think about their own feelings and responses to that message. Consumer and carer stories carry important messages and they have greatest effect when their message stays with the audience even when the details of the actual story are forgotten.

Different cultures have different traditions about the role of storytelling. Many of us have only experienced a culture where stories are told to children or as amusing anecdotes. The term ‘storytelling’ is sometimes used when adults are chastising children for fibbing or exaggerating. It is also sometimes seen as the opposite of ‘science’ – stories are, by definition, ‘untrue’, as ‘science’ is, by definition, ‘true’. Some cultures do not have a strong tradition of learning about life, customs, beliefs and values through stories. Because of this storytelling is often associated with entertainment. It is important in telling your story as a way of teaching others that you think about how to encourage learning. What questions are you going to ask your audience? Do you have an activity designed to bring your listeners into the story so that they think about their own behaviours and attitudes in relation to it. Sometimes a story on its own is not enough.

**Using other people’s stories**

Spontaneous storytellers can be a delight and are an asset to any community organisation which is called on to participate in this way. However be careful that you do not accidentally leap into a story that does not belong to you. If this does happen, the ethical thing to do is to contact the person concerned, own up and apologise. Most people will be understanding about it.

There is a widely held belief within the consumer movement that people own their own stories. This may be particularly relevant to those consumers whose story involves the life of a carer or to carers whose story is about the life of a consumer as well as about their own.

Ideally consumer and carer, consumer and consumer or carer and carer should get together and tell each other the stories they intend telling publicly. This is a way of making sure that the understanding of the story is shared and, if it is not, that each person involved is aware of and reasonably comfortable with the different understanding.

Sometimes it is not possible to get together with the other person whose story overlaps your own. A story might involve a description of something that happened in an acute hospital setting and it might include mention of another patient who cannot be contacted. In this case, every effort should be made to disguise the identity of that person.
Paradoxically, if he/she can be contacted, it is unacceptable to camouflage the identity of another consumer or carer without permission. Some consumers and carers who are active and open about their experiences want their stories to be told as part of a campaign against stigma. Remember, too, that strategies such as identifying individuals by first name only might be offensive to some people. Whenever possible, speakers need to contact those they wish to include in their stories, send copies of written material or tell them what they intend to say.

An example of a story: Pink Mugs

It was in the first few months of a new project and I had started conducting interviews with a variety of people. Here I was sitting on the grass with a woman in her twenties. We were both in the grounds of an acute facility. I purposely had not brought over my little tape recorder because I knew just too well that acute hospital settings are places of mistrust and I did not want to add to that. I tried not to take too many notes and the notes I took were always (absolutely always) open to scrutiny by the person I was talking with. With that in mind I never wrote commentary. Everything I wrote down was as close as I could get to the person’s real words.

But this was to be an important interview and one which was to genuinely influence my future work and attitude towards research and evaluation.

I was sitting beside this woman on a small hill. It was a nice day. I felt a bit uncomfortable – was I intruding? You know the sort of thing. It felt better when I got out my tentative list of questions. This gave me structure and a role to hide behind. Later I was to question my own motives in seeking such reassurance. I asked a few general questions about how she had experienced admission and how she was experiencing her stay. The next question was about the food. It seemed straightforward enough so I asked, ‘How have you found the food?’ – implication: do we need to complain about the food?

The woman’s reply will remain with me. She was sitting on the grass and I did not notice the mug she was holding in her right hand which was on the other side of her body from where I was sitting. She pulled the mug up and showed it to me. It was pink and it was plastic. Immediately I could imagine it with a stencil of a teddy glued to the front. She turned it upside down emptying the remaining coffee onto the grass and showed me her name hurriedly scribbled on a piece of tape and taped to the bottom of it.

‘I don’t think the real question should be about the food’, she said.

‘Just look at this mug. It makes me feel sick. I am angry-sick. I feel powerless to assert my right to be treated like a grown-up. I am a vet. Outside of this place I am held up as someone with an important and respected. . . and now? I have been reduced to a b——— plastic cup. How am I ever going to get over. . . ever recover? If I object, someone will find that this is me “acting out” or “attention seeking” or any number of negative things. It doesn’t matter about the food. I guess I can eat anything if it comes to it, but how am I going to get over this?’

Box continues on the next page
There was a good woman who worked on the unit. I asked her about the pink mugs. The arguments given in favour of the pink mugs have their own validity from a service provider point of view:

- Porcelain cups, the argument goes, are not appropriate in an acute unit where there is a duty of care on the part of staff. China might be broken – either deliberately or accidentally – and a dangerous situation might develop.
- People who are presently ‘in our care’ have to learn new skills in order for them to go ‘back into the community’. One of these skills is to take responsibility for their own possessions. ‘Such a lot gets lost or stolen around here. If patients have their names on their mugs then they are responsible for that mug while they are here with us. This is all about responsibility’.
- We have such a lot of depressed people (especially some of the old ones, you know) and we chose pink as a colour that will brighten the place up a bit and add to the pleasant environment created by the new furnishings.

These arguments have a logic. This is simply an issue about duty of care. But, from a consumer perspective, it is much more complex than this. It was the symbolism associated with the pink plastic mugs which was making this woman sick. It was this sickness that frightened her. It was from this sickness that she was afraid she may never recover.

Because, you see, from a consumer point of view, the mugs had other important messages:

- You are not an adult and do not deserve to be treated like one,
- Somebody around here is dangerous and you should be afraid,
- ‘Be a good girl and everything will be all right ...’.

There are fundamental and important differences in the understanding of consumers and providers and yet, in most settings, there is very little opportunity for the two groups to exchange this understanding and to learn from each other. It is around these sorts of fundamentals that we have promoted the concept of ‘deep dialogue forums’. Without them, we believe, apparently harmless acts and artefacts of service will continue to cause deep pain and endanger recovery.

Finally, this story is also about science. I learnt something that day on a green hill outside the acute unit. I guess even I (a consumer myself) had not thought to ask a specific question about pink mugs. It became obvious to me that not only does research and evaluation need to be generated by consumers and for consumers (honouring their way of experiencing services), but it also needs to constantly ask consumers to generate the questions. How often have we (as researchers this time) asked the banal and the pointless, only to find that real learning could have come about if only we had sought advice about what questions needed to be asked?

References
Organising workshops

Preparation
Thorough preparation is essential for a workshop to run well.

Timetable
Construct a timetable with a running sheet showing the order of activities. This running sheet needs to include ample time for breaks. Breaks also provide a good opportunity for informal networking. The timetable needs to be balanced with a range of activities and alternate between structured and less structured work. When starting to plan for a workshop for consumers and/or carers it is useful to consider the following:

- Always try not to start before 10.00am so participants can avoid peak hour traffic. If people are coming in from outlying areas you may wish to start even later than this.
- Even though it is tempting to fit as much as you can in, don’t. Breaks need to be frequent and long enough for smokers to comfortably finish a cigarette.
- Try to finish by 4.00pm, as many people use public transport to get home.

Workshop kits
You may decide to provide workshop participants with kits that they can take away with them. These give participants a visual cue which aids memory. It also helps people to ‘own’ the workshop and respect what it has to say to them.

It’s important for workshop convenors to think about the messages that they might want such a kit to convey.
Some Specific Activities

3.3 Organising workshops

It’s useful for convenors to ask themselves some of the following questions:

- How do you want this kit to look? If it’s ‘flash’, what will this say about the organisation or about you as a consumer or carer? If it’s casual, what message will this give?
- How much money do you have?
- What needs to be included? (Pen, but think carefully before including pens provided by drug companies; notepad; some cartoons; some quotable quotes; promotional material for the organisation; a booklist.)
- Do you want to combine the politics of consumer and carer issues with other important social and environmental issues? For example, should you make notepads out of recycled paper? Should the name tags be recycled ones? Should the bag be a cloth one rather than a plastic one? Perhaps you can only afford a cardboard envelope?
- Have you prepared an evaluation form for participants?

Venue

Venues need to be organised and booked. Think carefully about what you need in a venue as well as the costs. Access to the outside is particularly important because there may be some smokers. Will you need wheelchair access? Are there ramps and a toilet with wheelchair access? Think also about the space. Will it be easy to divide the participants up into small groups? It is preferable to book a room without fixed seating so that it can be reorganised to suit the mood of each session. Also avoid lecture theatres and other venues which dissuade people from interacting with each other.

However, there is another thing to take into account when choosing a venue. This has something to do with the ‘tone’ you want to encourage or the ‘atmosphere’ you want to create. It is, for example, a useful idea to plan a workshop for service providers in a consumer (or a carer) place, such as a consumer or carer ‘watering hole’ or meeting place. By doing so, you automatically send a consumer-empowered message before the workshop even starts. Always make sure that all this is organised well in advance with others who use the building.

The counter argument to this is that the workshop may be less well attended because service providers may find it more difficult to access. One of the common bits of juggling that consumer and carer workshop organisers have to do is to weigh up the pros and cons of a venue which is accessible by car (which tends to suit a majority of service providers), or accessible by public transport (which tends to suit a majority of consumers).

Arrangements must be made for catering (such as coffee and tea, biscuits, sandwiches) and equipment (such as overhead and slide projectors, whiteboards, butchers paper, stands). If these are being hired, check with the hiring company a few days before the workshop to make sure that they have got the order straight. Check that they will come to the right door at the right time on the right day. These details are sometimes not the responsibility of the consumers or carers who run the workshop and are arranged by the auspicing organisation. Even so, it is important to check that everything has been done as promised.
Think about money
It is important that you have thought about the possibility of reimbursing participants for the cost of their public transport travel to and from the venue. They will want to collect this on the day. It is very difficult to concentrate on greeting people, doing registration, reassuring them when they first arrive, preparing the room and counting out correct change at the same time.

Always make sure that you:
- Allocate someone else to deal with both the registration (signing people in and giving them workshop kits and name tags, if you are using them) and reimbursing travel costs.
- Have been to the bank and have an adequate change float to reimburse everyone.

Arrive early enough to set up the room the way that it will work best for your purposes and to test that everything is working. Preparation needs to include such details as checking to see that whiteboard markers haven’t dried out and that the butchers paper has been put in your backpack or in the car.

Planning activities
Workshops are generally more interactive than lectures, talks or other forms of presentation. Frequently they cater for fewer people. A good rule of thumb is to aim for about 15 participants.

Often workshops start with a warm-up or getting-to-know-you type of activity. This might be as simple as going around the group asking everyone to introduce themselves. Another simple introductory activity is to ask people to break off into twos and tell each other about themselves. When the whole group comes together, everyone has the responsibility to tell the whole group what they have learnt about the person they were listening to in their pair.

It is a good idea to have a mixture of activities to take account of the learning styles and backgrounds of a range of participants. It is also a good idea to vary activities between those which require people to get up and do something and those which require participants to listen. These activities might include:
- Talk or lecture, maybe as an introduction (no more than 20 minutes).
- Working in groups facilitated by trained consumer or carer facilitators.
- Working in groups without trained facilitators but with people from the group designated to collect the thoughts of the group to bring back to the whole session.
- Facilitators bringing back discussion from the small groups. (This feedback of ideas and perceptions to the whole group is sometimes called a ‘plenary’ session.)
- Games and other activities played in small groups or with the whole group – these might include role-plays, board games, interactive activities. (Also see: Some forms of consumer and carer participation in the Knowledge and Attitudes Booklet.)
- Some sort of written evaluation exercise.
Hint: When working with groups which do not have trained facilitators, always remember to ask the whole group if they need to add anything to the retelling of the group’s discussion by the designated note-taker.

When planning for appropriate activities, it is important to consider the following:

- The local context.
- The number of participants.
- Who the participants are: their cultural background, social class, race, gender, traditions or shared histories. (You know perhaps that many consumers would have experienced some of the powerlessness of being labelled mentally ill, or that many carers would have experienced the feeling of responsibility for the illness around them.)
- The comfort level – will participants feel comfortable doing the activity at this stage in the workshop?
- Objectives – what will this particular activity achieve?
- The design – at what particular point in the workshop should you do this activity? Should you use it to draw out a particular experience or to analyse something, to give more information to the group, and so on.
- The time of the day (for example, people may get ‘dozy’ after lunch).
- Language – level and literacy.
- Space and logistics – it’s useful to book the room and see it well in advance if possible.
- The materials and technology available/required.
- Theme/subject matter.
- The resources available to you.
- Participant experience – are you aware how much they already know about the theme?
- Organisational context/timing – who will need to be involved in giving presentations and when.
- Your own particular fears (or things you hate doing) and potential resistance to the activity.
Using butchers paper

Other aids which might be useful are overheads, whiteboards and PowerPoint program on the computer. (Also see 3.1: Presentation/education.)

Butchers paper is probably one of the most useful aids for less formal (more interactive) presentations such as workshops.

If you are collecting ideas from your audience, butchers paper is useful in several ways. Participants can write up their ideas on a particular topic or issue – say in groups of 3 or 4 – then each group sticks their paper to the wall. People can then walk around and see each other’s views. At the conclusion of the workshop you can remove the paper easily, take it home and transcribe the information into a report to go back to the participants or to the organisation which is sponsoring the workshop. Another way is to reduce and photocopy the butchers paper – this is awkward but achievable – for use at a later stage to indicate to participants that their contributions are being valued and used.

---

Group 5

What do we fear about consumer participation in our service?

1. That it’s only talk - no one really knows how to do it.
2. Only loud clients will say anything.
3. That women won’t join in.
4. That other staff will treat it like therapy.
5. That it’s tokenistic!!
6. That I won’t know how to do it.
Dealing with resistance

Resistance can occur in many settings but, in formal presentations, it is quite difficult to deal with directly. Some of the strategies outlined below can be adapted for use in question time following a formal talk or lecture. However, they are clearly more applicable to workshops, discussion groups and so on.

When confronted by new ideas many people feel threatened. This can lead to resistant attitudes and behaviours, even when the people concerned are not conscious of their underlying fears. At the same time, there are some people who resist an idea or point of view from a well-thought-out position. Active resistance from participants can provide a presenter with important reassurance that he/she is at least being heard. It is sometimes the passive person who says nothing who may be learning the least.

Tips for dealing with resistance (adapted from Arnold. R, 1991)

- **Discover the real agenda.** Pose questions that require people who are resisting to clarify what they mean and what they want. Often what people don’t say or what they signal non-verbally is what they mean. Make sure that you’re not spending time on diversions from the real point.

- **Give people the benefit of the doubt, initially.** Social change education requires a belief that people can and want to do the right thing. This means that you need to listen to and think about the experiences and sources of information that have informed the opinions of people who are resisting.

- **Confront the issues.** Summarise what you hear the person saying. Encourage other participants to get involved. If no one else feels able, don’t back off. Use the facts and resources you have available. Pose questions which probe the position taken by the person who is resisting. Know where you stand on the issue and explain what you are doing and why you are doing it.
● Don’t belittle any person who is resisting, even if she or he is behaving in a difficult manner. If you counter-attack, the other participants may close ranks against you – even if they tend to agree with your views.

● Ask other participants for their responses. If one person has had ample time to vent opinions or feelings, ask what other people think. This will prevent a limited exchange of views (that is, between facilitator and person resisting), and encourage more participants to take responsibility for how they spend their time.

● Be prepared to be flexible and adapt your approach if this is required. Most resistance is not sabotage. If several people have concerns about moving on before a particular issue is explored more fully, propose a change of emphasis to the group. This will allow you to address the anxieties or concerns you are hearing. Encouraging thoughtful resistance means taking it seriously so that it informs the process of learning.

● Use resistance for new insights. See if you can relate the resistance (as a kind of case study) to a larger issue the group is examining. Encourage people to derive new insights from what is said and how it is said.

● Know when to move on. At some point you may have to agree to disagree. At this point it is useful to restate the different positions, emphasising points of agreement and disagreement. Then you have to agree on a process for moving on. First, you may find it useful to take a break.

Evaluation

A challenge for consumers and carers is to feel comfortable and confident enough to seek and genuinely respect the feedback that comes from participants. This practice also provides an opportunity to experience a situation from a staff point of view. Consumers and carers have been arguing that service staff need to learn how to deal with constructive criticism from consumers and carers. To understand how threatening this might be to some staff, it is useful for consumer and carer organisers to put the shoe on the other foot and plan how they can routinely seek feedback from workshop participants. It can be useful to consider the following questions:

● Are you tempted to pose feedback questions in a way that invites participants to respond positively?

● When you get written responses and one is critical, are you tempted to try and work out who wrote it, and then construct a reason for the criticism that places responsibility on the respondent rather than owning it yourself?

● How will this evaluation exercise help you to change the things you do so as to do it better next time?

● What sort of debriefing can you put in place that will enable you to invite constructive criticism from participants without you collapsing into a self-critical and unproductive heap?
Feedback can come in more or less formal ways
If you are doing this work frequently, it might be useful to purchase a memo book to write down incidental comments and to paste in bits and pieces of feedback which come in unsolicited and unusual ways. An example of unusual and unsolicited feedback occurred when one consumer was asked to stay for lunch after she had given a talk to a group of people. As she was sitting at the table making polite conversation she was passed a note written on the back of a paper serviette. It said simply, ‘That was fantastic. Thank you so much’.

Evaluation does not have to come at the end of a workshop. As people become more experienced they will begin to start asking participants for feedback as part of the process of presenting the workshop. Below are some useful questions to ask participants. The answers to the questions will then help the workshop convenor to adapt the process as he/she goes.

- What are you learning? How are you feeling?
- How is the content useful? What else do you need?
- Who has participated? Who hasn’t? Why?
- How is the pacing? Is it too fast? Is it too slow?
- How is the balance between new and familiar content?
- How is the language level? What has been clear? What has been unclear?
Working with others
(Also see 3.4: Attending conferences)

Sometimes people are asked to work alone as presenters, educators or facilitators, but a more common requirement is for an organisation or group to be asked to provide several people.

**Learning to share the stage takes practice.** Some people work really well together and ‘feed off’ each other’s contributions. People tend to know when this works and the audience responds by being attentive, asking questions and getting involved. Some people find it easier to organise the session more formally, taking turns to speak or direct activities.

It is important that two people working together to run a workshop share the same values about the material they are presenting. For example, if they are consumers running a workshop for service provider staff, they need to share the same values about such things as:

- The intrinsic worth of the consumer or the carer point of view,
- The need for change in staff attitudes,
- The power of unkind and disempowering language,
- The purpose of the workshop.

In practical terms, this may translate into an already (pre-workshop) decided way of tackling things, for instance:

- Participants who automatically use clinical language which consumers deem to be insulting,
- Participants who dominate discussions,
- Participants who don’t participate,
- The power relationships between different professional groups in a mixed group setting,
- The power relationships between service providers with different levels of seniority and authority,
- ‘Dumping’ on administrators who may not be there to defend their positions.

This does not mean that two consumers or carers working together need to agree on everything! Indeed to disagree in front of a group of service providers and to have a sophisticated discussion about it in front of participants who might have stereotyped ‘the real consumer’ as someone who is not capable of this is a useful teaching device. The sorts of issues where there may well be different ideas are:

- Relationships with staff,
- Use of drugs,
- The ‘medical model’,
- Gender issues.
As individual presenters and workshop coordinators become more experienced, they will develop both a better idea of how they prefer to work and of who they do or do not enjoy working with.

It is important when you are working with someone else for the first time that each of you watches his/her timing. If someone has planned to speak for 20 minutes, for example, it is very frustrating and unnerving to be left only ten minutes to speak.

Politically experienced consumers and carers might choose (or be asked) to work with someone who is just starting out. Inexperienced people can gain a lot of confidence through this kind of supportive mentoring.

References
3.4 Attending conferences

Conferences can be really exciting. They can also be very daunting. They are certainly exhausting. This is because people are often involved all day attending paper presentations or workshops. Some people may be delivering a paper of their own. Or – perhaps even a little more exhausting – attempting to network informally with people from all over the place. The effort involved in exchanging names and addresses, discussing the last paper, buying a tape of a keynote address and generally making the most of the opportunities takes its toll. Then too, the socialising often keeps going well into the night, frequently accompanied by the sharing of alcohol and the toasting of friendships – new and old. No wonder people get tired!

Conferences are fun, but consumers have found that attending a conference can sometimes trigger illness. People who fear that this may happen to them need to plan well before the conference to minimise the likelihood.
Before the conference

Finding out what’s on

One of the strange and interesting things that seems to happen is that some groups of people always hear about conferences while others never do. If you are lucky enough to be one of those people who routinely hears about such events, remember that others may be interested. Take any flyers, you have to consumer or carer group meetings to show to others.

Service providers also need to be reminded that consumers and carers are interested in hearing about upcoming conferences and need to share advance information with them.

Interested people should make a habit of looking at public notice boards in clinics, services and in consumer or carer organisations where flyers are often posted. (And remind staff to take down old flyers, as there is nothing worse than getting all excited about the conference only to find out that it took place six months ago!)

Reasons for attending a conference

It is a good idea to be clear about why you wish to go to a particular conference. This helps considerably when it comes to setting priorities later on.

● Is there a special consumer or carer stream that might be interesting? Is there a symposium on something that you see as particularly important, such as ‘Adult Survivors of Child Abuse’?

● Is there a ‘consumer day’ or a ‘carer day’? – days set aside for consumers or carers to meet and establish networks and sometimes reach agreement on a position which they can take to the main conference gathering (the ‘plenary’).

Practical considerations

● Are there special reduced fees for those who are unsalaried? Does the consumer day mean an additional cost?

● Will there be affordable accommodation? What about billets?

● Are there any additional costs at home, such as child care, boarding for cats/dogs?

● How do you find out about special places for consumers? (For example, the Mental Health Services conference pays for some consumers to attend each year.)

● Does your local State mental health service subsidise the attendance of consumers who are presenting papers? If not, can they be lobbied to do so?

● Is there a group of consumers going together from your State? How can you get your name put on a list for this more economically viable option? What are the pros and cons of going with a group such as this?
Start packing
It’s probably a good idea for people to make a list and pack systematically. Don’t forget there will be a conference kit of some kind and this will need to be packed to come home. The kit usually contains pens and paper, so you may not need to take any. Inexperienced travellers might find it useful to enlist the help of a more seasoned person. Do not forget registration papers and travel tickets!

Preparing to give a paper
A range of ideas and strategies are given in 3.1: Presentation/education.

During the conference
Pacing yourself
As soon as you get your conference schedule, it’s useful to have a look at the timetable and mark the items that appeal to you. If there are three sessions in the one venue at half-hourly intervals, it’s advisable to plan to stay put. You probably will not have time to move between rooms and constant movement can be distracting for others.

Be wary of filling up all available time with attendance at formal presentations. Most people say that it’s important to leave themselves time for informal chatter and networking. Depending on the length of the conference, think about taking time out for one full day or maybe a half day. Make plans for this day, say, for shopping, going to the beach, a bus tour or bushwalk.

It is important that carers and consumers do not give themselves a hard time if they feel the need to take some time out during a conference. This does not compromise your integrity even if a service or consumer organisation is paying for your attendance. Rather, it is setting an example to other conference participants about good preventative mental health practice.

Representing an organisation or other consumers or carers
Organisations and groups quite commonly send a small number of consumers and/or carers to as many conferences as possible. This practice is an efficient way of bringing new ideas or insights into the group for the benefit of all members.

Those who are in this situation need to try to attend as wide a variety of sessions as possible. This can be made easier by finding out what sessions are of interest to others in the group prior to leaving home. It is probably best not to make promises but rather to take careful notes about others’ interests and do the best you can without burning yourself out.
At the conference, there will probably be tables with books, pamphlets, newsletters and other ‘freebies’. Look for these on the first day because the good ones run out quickly. Don’t feel embarrassed about collecting them, as someone will soon let you know if there’s a problem! **These can be great resources to take back to your group.**

People who have been asked to report back to a group might like to take notes or, perhaps, to ask significant speakers if they can provide a copy of their paper.

It’s a good idea to put notes into the form of a report as soon as possible after the conference finishes. This can be done by following a few simple word clues:

Report of ...............................................

**Who** was there/who spoke/who will benefit,

**What** was said/what was its relevance,

**Why** it was successful/boring/awful/painful for you/other.

**If you are in the position of speaking on behalf of an organised interest group** to which you belong, the views, suggestions, questions, concerns you are expressing need to be those of the group, not your personal views. While there may be differences within the group, majority consensus can be reached through discussion, paying attention to feedback on proposals, plans of action and through respectful attention to diverse experiences and ideas.
After the conference

Winding down
Conferences can be full of ‘hype’. If possible try and stay an extra night at the conference motel/hotel. Ask around and see if someone else is staying and, if so, arrange to do something together: have a quiet meal, go sightseeing, take a walk, catch a bus/train/ferry or go out and do some retail therapy. There’s a lot that can be done in a strange town in half a day.

Some politically experienced consumers have suggested that people ‘play the transit’ (the public transport system) for half a day. They report that it’s good fun and of minimal cost. In the afternoon sit down and write up a report for your group. Writing is a way of ‘using up’ memories which may otherwise start to go whirling around and become over-stimulating.

If you have given a paper, facilitated a workshop or made some other kind of presentation, it is quite possible that you will feel ‘down’ afterwards. This can happen whether your presentation went well or not. For some people this is a natural reaction following the excitement of speaking in public. If you do experience this kind of reaction it is important to make contact with other people (straightaway if possible) and talk it through – don’t brood on your own.

Debriefing
When you get home, there are obvious things that need to be done. For people who may still have memory-whirling problems, politically experienced consumers suggest a number of things from physical exercise to ringing a few friends for a whinge or rave about the conference. (Also see 2.1: Briefing and debriefing.)

Writing up papers for publication
If you have presented a paper or workshop session at a conference you may be asked to submit a written version for publication in the ‘conference proceedings’.

Conference organisers usually have strict guidelines and clear directions about how papers to be published in the conference proceedings need to be written up.

- Typically you will be asked to submit your manuscript in double-spaced type of a particular font and size. You may be asked to submit both a hard copy (on paper) and a copy on computer disk, in which case a range of acceptable programs will be specified.
- Your written paper will not be a word-for-word version of your spoken presentation and this is perfectly acceptable. There are some important differences between what
reads well and what sounds good.

- Illustrations (slides, overheads, posters) – the guidelines will inform you how these need to be presented for publication
- Proofreading, careful reading and editing, is very important. Not only should you check your own work but (if possible) get someone else to check it as well. Another person can often pick up ‘typos’ and other errors that you may miss.
- There may be problems for conference presenters who do not have access to the necessary equipment (such as a computer) to meet the publishing guidelines. If this means that consumer and carer contributions are consistently missing from, or under-represented in, conference proceedings and journals, then a range of important views fail to reach the potential audience. Consumer and carer organisations may be able to help here, or contact the conference organisers. They need to know that these issues exist and that they need to be addressed.

**Copyright and ownership**

When someone ‘publishes’ their ideas, whether written, spoken, electronic or graphic, that material is considered copyrighted to the ‘author’, organisation or publisher. In most cases you can refer to and quote from written material (in books, journals and other documents) as long as you acknowledge the copyright holder/s.

A direct quote, whether spoken or written, should be enclosed in inverted commas (‘...........’) and provided with a reference – a footnote¹, endnote² or in parentheses (in brackets) immediately following the quote.

The reference needs to include name of the author/s, date of publication, title of the book or article (and, in the latter case, the name and volume number of the journal), publisher (for book), city where published, page number/s.

In addition, all books/articles cited (used) – whether directly or in an adapted form – need to be included in a bibliography or list of references. These are organised...

...It is important that we don’t take the idea of consumer involvement lightly or tokenistically.

‘If agencies aren’t clear why they are involving people, how to involve them or what people can expect from getting involved, then all their energies are likely to be unsuccessful. If people aren’t clear why they are getting involved, what they ought to be doing and what they can hope to achieve from it, then they are likely to end up feeling fed up and cheated’

Croft. S, and Beresford. P, 1993
Use or reproduction of pictures, cartoons, diagrams, video and audio tapes or complete texts can be more complex. You may need to contact the copyright holder. Often people will give permission for consumers and carers to use their work free but do not assume that this will be the case. Sometimes a fee will be charged.

Sometimes authors will write a message about copyright inside the front page of a book, or in an electronic publication. This might say: 'Please circulate widely. The content in this book is designed for consumer education and the author wishes it to be disseminated as widely as possible'. With a message like this you are obviously free to make use of the material – but you must still acknowledge your source.

References (an example)

1 A footnote is a reference which comes at the bottom of the page and is numbered so the reader can glance down to the bottom of the page to identify the source of the quote.

2 An endnote is like a footnote but comes at the end of the chapter rather than at the end of each page.

References
Report writing is important in many aspects of advocacy. Reports can be very brief or very large. The size of a report is no indicator of its worth. A good report states only what is necessary. Sometimes reports contribute to larger reports; sometimes they stand on their own. They may report on an activity or project, on a key issue, provide information or be analytical. Whatever the purpose of your report, there are structures and styles that you can use to make your report accessible and credible.

It is sometimes tempting to rush into writing a report, only to hear that the reader had difficulty understanding it. Usually reports deal with quite complex matters and demand some planning before the real work begins.

**Decide the purpose of the report**

Has someone asked you to write this report? Make sure you obtain a clear brief from the person, preferably in writing.

What is the central theme that you are addressing? Every report has a purpose. What are you trying to do? ‘To give an honest and representative account of my consultative workshop’; ‘To recommend action on increased consumer participation in service quality improvement’; ‘To provide information to my group on local carer support activity’.

**Define the readership**

Some reports are for general consumption, many are for a specific readership, perhaps only one person. Being clear about who the report is for can assist you in ‘tailoring’ it to specific needs.

A highly technical report is of little value to people who lack the technical background to understand it. A highly detailed report is inappropriate for a person who prefers to make decisions ‘on the run’.

**Develop a structure**

If your head is full of ideas, write them down in any order before you forget them. Put them aside for a while as you work out the structure of your report.

Draw up a list of headings and subheadings for the main body of your report to help you organise the sequence of your discussion. Plan the order of your paragraphs so that each one contains a single point. (An example is shown on page 159.)

Reports tend to have similar features that provide for logical flow and make it easier to find things. Depending upon the size and formality of your report, you can adapt the following:
Title page
Create a strong, concise title that indicates what the report is about.
Let the title stand out so that the report is not overlooked. Write your name underneath and enjoy the credit.

Acknowledgements
Sometimes other people may contribute to your report. They deserve to be acknowledged. Mention them by name, but check with them that this is okay.

Foreword (optional)
A foreword is a bit like an introduction, but often written by some prominent person to add credibility to the report.

Contents, appendices and figures (optional)
If the report has many sections and pages, a contents list is important to enable the reader to find what they want. Adding the appendices list to the contents will assist in the reader locating them. Your report may also contain figures, tables and charts. It is usual to number these in sequence as they are used. A list of which pages to find them on is useful for someone who wants to refer to a particular figure.

Summary (optional)
A long report can benefit from having a summary. Often the people that the report is meant to influence claim not to have the time to read it right through.

Providing a summary enables the important points to be stated without the need to read the whole report. The summary needs to carefully pick up the main purpose, issues, supporting evidence and recommendations, and be able to stand as a condensed report in its own right.

Note: All of the preceding sections need to be completed after the following parts of the report are written.

Introduction
State clearly how the need for the report arose and any relevant background information. If the report is complex, you may want to let the reader know the structure of the report by giving an overview of what they can expect to find in each section.
Background (optional)
You may find the introduction is an inappropriate place to provide a full background on complex issues. In this case, a separate background section is useful. The structure of this section may provide a sequential account of the events leading to the central issues, or may explain the range of competing views and arguments one by one. It is important to provide the reader with some logical flow.

Note: In short reports the following five sections may be condensed into one. It is still useful to consider the use of subheadings to give structure to the report and to organise its flow for the reader.

Issues
This section explains the particular issues that are the reason for writing the report. They need to be clearly stated along with any additional commentary.

Process
Your report is likely to be supported by some evidence: a piece of research, a consultation process, some background reading. Your report carries greater strength when the process of gathering your supporting evidence is made known to the reader.

Findings
This section should contain the relevant outcomes of your inquiry. It may include some basic data and is likely to include your analysis of the inquiry. When presenting background information like figures and charts, use only those that support the main points. Put the rest in the appendices and refer the reader to them.

Conclusions
The previous sections may contain a wealth of information. You may need to use this section to draw the reader’s attention to the main points by briefly recapping on the issues and the evidence in support of your final position.

Recommendations (optional)
Your report may not lend itself to recommendations being made, you may have a list of recommendations or you may have only one. Be very clear about any recommendations being made. This is where you hope to invoke some action. Make sure the recommendations are logical. They need to be supported by your evidence. A poor recommendation can spoil an otherwise great report.

Appendices (optional)
Place all of your relevant supporting material in the appendices rather than clutter the body of the report.

References and bibliography
If you have in any way used the written work of other people, you need to clearly acknowledge this. Where you have quoted or heavily relied on the work of others, they must be referenced either at the foot of the page upon which they are identified or in a list of references. Where you have undertaken reading of the work of others to formulate your views, the work should be listed in a bibliography. (Also see 3.4: Attending conferences.)
**Undertake drafting**

Careful planning will reduce the need to create many drafts. You should aim to produce a document that requires one review before completion. Practice will help you to do this.

It’s easy to become very involved in your work when writing a report. It’s often useful to put the report away for a while, at least overnight, to create space for yourself from which to return with fresh ideas.

If you’re intending for another person to read the draft before completion, give them enough time and be specific about the purpose of this. Do you want them to check the soundness of your argument, its readability, the grammar?

**Writing style**

Be simple in the way you write. Use short sentences that are clear and direct. Avoid the ‘shorthand’ that develops within a group that others may not understand. Avoid slang and jargon.


Create space between yourself and the issue. You may be passionate about an issue, but the readers of formal reports will usually be persuaded by rational argument, not emotional appeal.

**Logic and argument**

Create your argument through a series of logically connected statements that lead to a conclusion (A then B then C leads to D).

Make sure that the assertions you make about the cause of things are logical and readily demonstrated (B happened because A happened).

Do not argue from ignorance – that something is true simply because it has not been proved untrue, or that something is false simply because it has not been demonstrated.

Don’t appeal to false authorities – it must be true because I heard someone say it on the TV. Be satisfied that the person has the evidence and facts to make the statement.

Be cautious about appealing to ‘common sense’. It may not be as common as you think. Conventional thinking has been demonstrated to be incorrect in the past.

Be careful about making generalisations from small examples.

**References**

Developing a structure for report writing

Preamble
● Introduce reports, structures and planning

Purpose
● Get a brief
● State a clear purpose

Structure
● Ideas
● Headings
● Sections
  • Title
  • Acknowledgements
  • Foreword
  • Contents, Appendices and Figures
  • Summary
  • Introduction
  • Background
  • Issues
  • Process
  • Findings
  • Conclusions
  • Recommendations
  • Appendices
  • References and Bibliography

Readership (who you are aiming it at)

Drafting
● Planning (decide how you will proceed)
● Space (decide where you will do the drafting)
● Other people (decide and organise those who will assist you)

Style
● Keep it simple
● Avoid shorthand and jargon
● Use an impersonal tone

Logic and argument
● Create connections
● Demonstrate cause
● Don’t argue from ignorance
● Don’t use false authority
● Be cautious about common sense
● Don’t generalise from small samples
3.6 Submission writing

You may want to put forward a submission, say, for a new service or in response to an advertisement for a grant application. Many of the steps outlined in 3.5: Report writing are applicable to writing a submission. One major difference between the two is the purpose of the document.

A submission is created within a competitive environment in an attempt to win an outcome. The submission is usually directed towards actively persuading someone to support your position above another. While needing to be logical and sound, a submission will often put forward a good idea, the evidence for which may not be readily to hand. The idea may have been formed, for instance, from the observation that something similar appears to work elsewhere; anything is better than nothing; there is a strong ‘sense’ that this idea is a considerable improvement on what currently exists.

Be clear about what is possible

Submissions are often written in response to an event, for instance, the redesign of services or the release of funding. For your submission to rise above the others you need to be clear about what is possible.

- Find out as much as possible about the presenting opportunity. Identify and talk to key people such as the nominated departmental project officer or the local service manager.
- Attempt to find out how acceptable your ideas are to those making decisions by contacting them and talking through the main points of your submission.
- Where possible, find out what the competing interests are, the strengths of competitors’ arguments and how favourably accepted they are by decision-makers.
- Read a copy of the application details as soon as possible. Make contact with the authorities to clarify any uncertainties.
Take stock of attributes

You may be applying for a grant to manage a project or a service. Usually this will be as part of an organisation’s interest. The organisation and its prominent people are part of the submission. They will be judged on their capacity to successfully manage a project or service as much as on the proposal itself.

● Take stock of the organisation’s internal strengths and weaknesses. How does it fare in its capacity to carry through on the requirements of, say, a grant application? Does it have a suitable organisational structure, credibility, experience, the right people?

● Consider the external influences on the organisation. Does it have support from other organisations or influential people to carry through on the submission? How well placed is it in relation to its networks?

Gain support

Where an organisation is submitting to deliver a service or manage a project itself, consideration of the attributes of the organisation may indicate gaps in its capacity. It may also indicate the need to enhance its community standing.

● Consider strategic alliances with other organisations,

● Identify and co-opt people who can contribute particular knowledge or skills,

● Ask other organisations if they are prepared to write letters of support for your submission.

Get organised

● The turn-around time for submissions is usually short. Make sure the closing date is clear and plan towards meeting it.

● It’s always a good idea to have people put their heads together around the submission. In the end though, it is practicable for one person to write the draft submission, even if a larger group needs to endorse it.

● Develop a plan of action and make sure that arrangements are made for meetings, drafting and turn-around of documents within the required time-frame.

● Organise access to typing, printing and photocopying.

Define the purpose

● Submissions often start with a vague idea. For a submission to be successful, it needs to go well beyond that. It’s worth spending the time to be very clear about the purpose of your submission – to turn a vague idea into a concrete proposal.

● Before proceeding further, check that the purpose of your submission is in keeping with the context of the opportunity. For instance, does your proposal fit within the grant specifications? It may be that the title of it sounds right, for example, ‘To explore the information needs of people with disabilities’, but that the specifications particularly exclude, for instance, people with psychiatric disabilities. (This may provoke a different type of submission!)
Write the submission

- Start with a description of the impetus of the submission. Where did it come from – a public meeting, the outcomes of a research project, an advertisement in the paper?
- State the nature and dimensions of the problem that a successful submission will address – provide clear and concrete information. Describe your understanding of the cause of the ‘problem’ and what the ‘problem’ is – explain how you identify this cause/effect relationship.
- Indicate supporting evidence, including research reports, current best practice, policy guidelines.
- Describe how the ‘problem’ is currently dealt with, how adequate these approaches are and their deficiencies.
- Explain the possible alternative courses of action, their benefits and deficits.
- State clearly what your proposal is and how it will address the problem – describe the proposed methods and what will be achieved.
- Indicate clearly how the service/project will be monitored and evaluated.
- Describe the organisational and accountability structures.
- Indicate who will be responsible for what.
- Describe how and when reports, say, to a funding body, will be delivered.
- Describe the required budget (also see 2.8: Managing a budget).
- Create a schedule of tasks and completion dates.
- State the contact details of your referees.
- Give the details for the contact person for the submission.

Follow-up

Depending upon the circumstances a range of actions may follow. Be prepared for any of these eventualities. These include being:

- Invited to support your submission in person,
- Required to provide additional information,
- Requested to receive a visit from a funding source,
- Invited to send a representative to a working party or committee.

References

3.7 Chairing meetings

Committees come together for specific purposes, usually to make decisions or report on issues before them. While committee members may work towards common goals, they often do so from a diverse range of interests and views. Meetings of people can become unruly as participants seek the opportunity to have their say. The central role of the chair is to manage the committee to address the tasks before it.

You may want to adopt the following as a guide to chairing.

**Promote participation**

- Keep track of who is participating in the discussion and offer the opportunity for all members to contribute,
- Actively encourage those not contributing to do so without singling them out in an embarrassing way,
- Be aware of body language as a useful sign that people are not participating, for example, people sitting back or looking distracted,
- Consider doing a ‘whip-round’ to actively promote contribution, but do so sparingly – let people ‘pass’ if they want to,
- Encourage ‘long-winded’ speakers to sum up or focus on the key points,
- Pose strategic questions to engage people, such as, ‘What would it take for us to move from situation A to situation B?’

Commonly the chair is more of a facilitator than a contributor. The assumed authority of the chair can mean that his/her views carry greater weight in the discussion. Excessive interjection and expression of personal views by the chair is generally unhelpful to participation by others. Facilitation is a strength in chairing, particularly in less formal meetings or when the issues are especially difficult. As a facilitating chair, you can:

- Acknowledge the strength of group interaction and collective contribution,
- Use enabling techniques like ‘brainstorming’ and strategic questioning to free up member contributions,
- Believe in power-sharing and promote facilitation and leadership in others,
- Seek a high level of group ownership of the solutions.
Maintain order and guide discussion

- Be aware of the assumed authority of the position and use power and control sensibly. Your role is to keep participants focused on the issue. Some latitude is always necessary to allow people to explore the issue.
- Organise the agenda so that important decisions are made early while people are ‘fresh’.
- Ensure continuity through reviewing the proposed activities from the previous meeting before adopting new topics.
- Plan and manage the time to give fair attention to each issue.
- Assist the committee by stating what the general end point is to be and the parameters of the discussion. ‘We need to arrive at a collective position on...the issue has arisen because of...we have an opportunity to...but we are constrained by...’.
- Clarify where the discussion has reached if it appears to be stuck. Keep notes of the arguments and evidence so that you can, where necessary, summarise the discussion and indicate its current position in relation to the issue.
- Deal with conflict as it arises. Conflict between members is inevitable and can be constructive or destructive. Conflict becomes problematic when people personalise it. Monitor the discussion to ensure that people are not the target of the conflict. Personal attacks and statements like ‘You don’t know what you are talking about...’ or ‘Who are you to be suggesting...’ are strong indicators of conflict between people rather than between issues. Summarise the facts and the issues of the discussion. Identify the areas of agreement and move on from there. Introduce a break if the exchanges are too heated. Return with a rational introduction to the discussion. You may choose to adjourn the discussion until the following meeting and even talk to members about the issues in the intervening period.
- Encourage members to prepare a case on a particular issue prior to the meeting to enable concentration on the issues. Formal committees will often require this. Conflict often arises when contentious items are allowed onto the agenda without notice and members are not sufficiently prepared to respond. The chair has the right to postpone discussion to a further meeting.
- Monitor the course and pace of discussion. It is not unusual for a committee to get stuck on particularly difficult issues. Assist by altering the rhythm of the discussion and promoting innovation. Some useful interventions include graphically describing the issue on a whiteboard or butchers paper, breaking into small groups to consider parts of the problem, undertaking a brainstorming exercise. (Also see 4.1: Getting yourself and your organisation focused.)
- Understand the agreed procedural rules of the committee and invoke them impartially.
Achieve an outcome

- Some committees require that a vote be taken on a proposition that has been ‘moved’ and ‘seconded’. This is a traditionally formal way of achieving an outcome. You may want to satisfy yourself that, in taking this approach, particular members who are forced to vote ‘no’ have not been disempowered through lack of opportunity to state their case.
- Less formal meetings may engage in discussion that looks to ensure that everyone has had a chance to participate. As chair, you may put the proposition as a summary statement of the consensus reached such as: ‘So, it seems we are all agreed that…’
- Some committees adopt the rule that in the case of a tied vote, the chair has the deciding vote. While this may be expedient under certain circumstances, you may want to consider the consequences of exercising this power in relation to preferred impartiality. You may choose to defer the decision on the basis of further evidence that may impact upon the vote, seek a different outcome through modification of the proposition or open up further discussion. However, where it is futile to do any of these things then an assertion of leadership is the best choice.
- However the outcome is decided, it is important to remember that the committee is bound by the outcome. It is easy for a committee that is exhausted or not sufficiently informed about an issue to agree to a proposition without a strong commitment. Be aware of the level of commitment to an agreement and, as an alternative, defer a vote until more commitment is achievable.

For some committees, the challenge of note-taking requires special consideration. The ‘secretary’ or ‘minute-taker’ may be a rotating responsibility. Check that sufficient time has been allowed for all the important points to have been recorded and that the wording of proposals have been correctly recorded for the minutes. (Also see 3.10: Note-taking and minute-taking.)
- Clarify when someone has agreed to undertake further action, be specific about what that action is and ensure that it has been recorded in the minutes.
3.8 Being a committee member

To be approached to be a committee member can, in itself, be recognition of your worth. Participation is the means to empowerment and to accept the invitation is the first step. You may find the experience of being a committee member a good one. In many instances, however, consumer and carer participation has proven to require some negotiation to be effective and rewarding.

Consumers and carers may be members of many types of committee, from local service development committees through to committees that make very high level decisions. Two special conditions under which consumers and carers become committee members are worthy of note: those appointed for a special purpose and those who are consumer or carer consultants.

Appointees

Sometimes individual consumers and carers are asked to sit on a special advisory committee because they are well known. Such an individual might catch the interest of the media or be otherwise ‘marketable’. Consumers and carers acting in this capacity have a role that is sometimes misunderstood by others. A lot of what they are asked to discuss will be confidential and they will not be at liberty to share all their information with other consumers and carers.

These people are in a position of great responsibility as consumers or carers. Often they are selected because they are well known or because they are known to have a ‘network’. Perhaps they come from an organisation that has access to a network of consumers and carers. Although they are not representative (in the usual sense), a part of their responsibility is to think about how they frame the information and advice they put forward within the committee.

People might preface what they say with: ‘This is just my experience but ...’; ‘A lot of consumers/carers I have spoken with seem to be telling me that ...’; ‘As you all know I have a particular interest in ...’.

The critical responsibility here is on those putting the committee together. Each potential committee member will have her/his own set of genuine and important first-hand experiences. Each person will also have her/his own areas of interest. There needs to be a balance of interests and perspectives across the appointees. The need for balance must take account of such issues as gender, rural/urban populations, different diagnostic experiences, as well as others. For example, it would be pointless to set up a committee where every carer member happened to be the father of a male person living with schizophrenia.

Consumers and carers who are appointed to these committees can assist the creation of effective balance by speaking out.
Paid and unpaid consumer/carer consultants

Sometimes a group or committee will look for a consumer or a carer who is also known to have other skills required by the committee. The person chosen may be a consumer or carer who has set themselves up to provide consultative advice to the sector, or may be a consumer who has experience as a librarian, or someone who has teaching qualifications.

There are consumers and carers who become well-known as experienced operators. It should not be automatically assumed that these people are called on for advice because the committee, service or other body wants a ‘tame’ consumer or carer. This might be the case, but more likely they will be looking for experience. They will be well aware that in seeking out experienced people they will get consumers and carers with a greater capacity to influence the process and practice of the group. It is necessary that consumers and carers working as freelance consultants use their expertise appropriately.

It is appropriate for experienced consumers to undertake education of service staff in relation to setting up suitable structures for consumer participation to flourish.

It is not appropriate for consumers to be paid by a service for giving feedback about the quality of the service offered if they have not experienced it at first hand. This would be appropriate only if the consumers were experienced consumer consultants who had been engaged to find out what a representative range of local consumers thought about a certain issue or, for example, to determine the results of certain policy decisions.

Organising your participation

You may want to consider how empowerment can be enhanced through the creation and exercise of choices.

The following questions may assist you in organising your participation. If the answers are not clear to you, discuss the issue with your peers.

Be clear about why you are being invited

The story behind why you have been approached is important because it will tell you something about the values and attitudes of the people establishing the committee. By asking relevant questions, you will know more about their views on participation and representation.

- Where did the idea of the committee come from? Are you satisfied that you can work with the other members?
- Are you expected to be representative of a group of which you are a member?
- Are you being invited because of some personal skills or knowledge that you have?
- Is it because someone said the committee needs to have consumer or carer members and somehow you are approached?
Be clear about what is expected of you
As an equal member of a committee you should anticipate that expectations of you will be no different from that of other members. You may want to be assured that the expectations are not unreasonable and that adequate assistance is provided to committee members to participate fully. A few questions will assist you in determining whether you can fulfil the expectations.

- Will you be the only consumer/carer?
- How much reading or developmental work will there be between meetings?
- What kind of support will assist me and can it be provided?
- Is particular experience or expertise expected?
- Can you free-up sufficient time to make a commitment?
- Are you fully aware of any legal obligations (for example, under an Associations Incorporation Act)?

Be clear about what the committee is for
There are many reasons why committees form. (Also see: Some forms of consumer and carer participation in the Knowledge and Attitudes Booklet.) In making a commitment to membership, you may want assurance that this committee has the capacity to meet your advocacy needs.

- What type of committee is it?
- Is the purpose of the committee in keeping with your interests?
- Does the committee have the decision-making authority that will enable you to achieve your goals? Is it organised just to ‘rubber stamp’ the decisions of a particular person or group?
- Are the constraints under which the committee operates acceptable to you?
- Who are the other members and who do they represent? Do they share views that are similar to or different from your own?
- What can you learn from getting access to previous minutes and organisation reports?

Determine what value is being placed on your participation

- Have fees been discussed and what are they? Do they include both meetings and preparatory time? (Also see 1.8: The business end of participation.)
- Have any special needs been considered?
- Is everything in place that will increase your comfort and confidence to be a member?

Clarify the arrangements

- Do you know where to meet and when?
- Do you know how to get there?
- Are the arrangements acceptable to you?
Accepting the invitation

Accepting the invitation to be a committee member is a commitment to take on certain responsibilities. You may want to ensure that the conditions upon which you do this are acceptable to you. Some things to consider may include:

- Is this a committee you really want membership of?
- Is there sufficient support in place to assist your participation?
- Are any fees and allowances reasonable?
- If you are seen to represent other people, do you have sufficient ways of consulting with them?

Gaining support

As a committee member you may benefit from support. A number of options are worth considering:

- Discuss your concerns and any particular needs with the chairperson,
- Insist on not being the only consumer/carer on the committee,
- Approach a more experienced person to act as ‘mentor’ to you by assisting your appreciation of the issues and processes of the meetings and through explaining technical detail and jargon,
- Negotiate a back-up representative in the event that you may not be able to participate for a period,
- As a representative of an organisation, check out whether you have delegated authority to make decisions on behalf of the organisation; establish a clear line of reporting back to the organisation; make sure you have mechanisms in place to know what the organisation’s view is on various issues.

Preparing for meetings

Committee membership carries with it a responsibility to participate. You need to be prepared to address the issues before arriving at the meeting.

- Insist that you have access to all the information necessary for you to participate – make sure it is available in sufficient time and in an appropriate form for you to consider it,
- Be clear about any expectations on your participation – if in doubt, check with the person who has raised the issue or the chairperson,
- Plan and set goals on your contribution to the issue rather than just reacting to someone else’s agenda – if necessary, check back with the people you represent,
- Depending on the rules of conduct of the committee, contact the secretary or chairperson and have your issues placed on the agenda – be prepared to speak to the issue,
- Arrive in good time – you will be more relaxed and may be able to do some lobbying among other members prior to the meeting,
- Make sure you have all the relevant papers with you and be prepared to make your own notes,
- As a representative, make sure you have organised links with your constituency.
Participating in meetings

Committees may be more or less formal in the way they operate. (Also see: Some forms of consumer and carer participation in the Knowledge and Attitudes Booklet.) You will need to know the rules and operate within them.

General impressions

It is important that the right person is selected to be on a new committee. The ‘pioneering representative’ can have a strong influence on the acceptance of consumer/carer participation over the long term. Consider creating a good impression by being organised, good-humoured, open, flexible, consistent and in performing positive tasks like:

- Bringing the discussion back to the point,
- Initiating a new issue,
- Summarising the discussion to date,
- Thinking of different approaches when the discussion becomes stuck,
- Blending comments together,
- Connecting points,
- Diagnosing a problem,
- Being inspiring,
- Relieving tension or creating useful tension,
- Helping others to communicate,
- Being an active but non-intrusive participant.

Speaking to the issues

Committees deal with agenda items. Usually they will result in some form of decision in which you will be expected to have participated. Some of the agenda items may be your own or have significance for you. The committee process is one that inevitably determines a collective position through majority support for an issue. If you are to gain what you want you will need to win the support of committee members. The following points may be useful to consider:

- Prepare yourself well. This usually means writing out for yourself the case that you want to put. Aim for rational, defensible argument rather than emotional appeal. In a rationalist society, emotional outbursts rarely win through. Keep it simple, to the point and brief. (Also see 3.6: Submission writing.) Find someone to rehearse it with.
- If you are a representative, satisfy yourself of the views of the constituency and represent them honestly, fairly and according to your mandate.
- Talk to other committee members about the issue and gauge the level of support. Find out how to contact them between meetings. Decide whether you need to abandon an issue, delay it or modify it to win through.
- At the meeting make it clear what decision you are looking for. This may need to be put as a ‘motion’. If the rules require it, you may need a ‘seconder’ to the motion. Ensure that you have a seconder prior to the meeting who is prepared and able to speak in support of the motion. Talk to the proposal from your notes.
- Listen attentively to responses from other members and allow them the opportunity to present their position. Be prepared to support alterations to your proposal provided they do not compromise the integrity of the argument. (Also see 1.6: Interpersonal communication.)
- If you are responding to the proposal of another member, argue for or against the issue from your own prepared position whenever possible. Attack the issue, not the person.
- Be prepared to accept defeat. You will not succeed with all of your proposals but good preparation will increase the odds.
- Report back to your constituency and seek further advice.
- Be prepared to appeal through the chairperson if issues are proposed for decision that have not been placed on the agenda or have not been given sufficient notice.
- If you are a representative, resist the pressure to participate in a decision without sufficient time being accorded to consult with your constituency, particularly where you have no delegated authority. Make clear the consequences of decisions being taken without due consultation.

**Process watching**

Where a consumer or carer sitting on a group finds that he/she is comprehensively outnumbered, he/she can fill the invaluable role of process watcher. **Process watcher** is jargon that refers to a person who is there to remind others just who the services are designed for. The role is to be the resident ‘pain in the neck’ to the committee by routinely practising some or all of the following interventions:

- Stop the conversation every time jargon is used and politely ask for it to be defined or for a better word to be found.
- Stop every time an acronym is used and ask, ‘What does that mean?’ (even when you already know what it means!).
- Announce, politely and in a surprised tone of voice, ‘I didn’t actually get my papers till last night. I’m sure that it was an oversight they were so late but could we just make sure it doesn’t happen again. Thanks.’
- Keep on asking, ‘How do you know that? Have you asked consumers? Have you asked carers? How? How many? Who wrote the questions? Who asked the questions?’ and so on.
Keeping organised
Participation will be assisted if you maintain some organisation of your own contribution.
- Committees tend to produce large amounts of documentation – keep papers in order using simple filing systems like ring-binders with dividers that you can take with you.
- Give yourself enough time to read background information. Make notes as you read – note your overall response.
- Provide background papers on your own issues and give people time to read them.
- Take your own notes at meetings as only the major points and decisions will be recorded in the minutes.
- Ensure the minutes are a true reflection of what occurred – make sure any of your dissent is recorded.
- Add to the agenda.

After the meeting
Completion of one meeting is preparation for the next.
- Be clear about the actions to which you have agreed and are responsible – ensure you know the timelines to produce a result.
- Follow-up on outstanding issues and items to ensure a positive outcome is possible.
- Reflect on the meeting and evaluate your own actions and those of others.
  (Also see 2.10: Reflection and evaluation.)
- Report back to those you are representing and receive any further advice.
- Prepare for the next meeting.

References
Beaumont J (1987) *Mastering the Meeting*, Information Australia
Canadian Mental Health Association (1994) *Board and Committee Survival Handbook for Consumers of Mental Health Services*, Kelowna, British Columbia
3.9 Being the ‘layperson’ among ‘experts’

The terms ‘layperson’ and ‘expert’ are often used but create problems. Just what is meant by each of them? In common usage these terms are set in opposition to one another: that is, the ‘expert’ is someone who has special knowledge and/or expertise, while the ‘layperson’ is someone who lacks that special knowledge and/or expertise. In the mental health field the all-too-common assumption is that professionals – service providers, service administrators, educators and others – are the ‘experts’, while the consumers and carers who fill consultative, advisory, educational and representative roles are the ‘laypersons’.

**Who is the expert?**

One of the most difficult challenges faced by consumer/carer advocates is the lack of recognition of their particular and important expertise. This lack of recognition is embedded in the culture and history of mental health services and, so, is extremely widespread.

In trying to put the issue of just who is the expert into perspective, you need to consider the field of expertise that is under scrutiny. It seems that confusion exists among some service providers as well as among some consumers and carers. The confusion is perhaps a carry-over from the days when doctors (and some other professionals) were regarded as demigods. They were thought to possess a superior wisdom and morality above and beyond their specific areas of qualification. It is a fact that, for some service providers and for some of their clients (consumer and carer), the myth of the all-knowing professional persists. However, the field of expertise in question is not, in fact, one in which service professionals carry all the knowledge and experience. The field includes the lived experiences of consumers and carers and everything these experiences have taught them.

**Recognise your own expertise**

The first step to having your expertise recognised by others is to recognise it in yourself. Acquiring skills and gaining experience; talking to other people who have ‘mixed it’ with the ‘experts’; making sure that you have a support network and so on can help you to believe in you own expertise. Confidence is a valuable commodity. Consumers and carers often have had their self-confidence seriously undermined not only by their experiences but, sadly, by the ways that they are treated within the services they use. No matter how skilled and knowledgeable you are you may lack confidence at times. This is when working alongside other consumers or carers can be of great benefit.
Try not to be overawed or intimidated by the fact that someone has a string of letters after his/her name, or speaks with the authority of his/her social and professional status. In some cases, consumers and carers may also have professional and/or other qualifications. Whether or not this is the case for you, remember that you are well qualified to give your expert views about your own life and/or the lives of those you represent.

**Believe in your own perspective**

Believe in the importance and relevance of your perspective and the perspective of those you represent. Consumers and carers often do not realise that, in many areas, they are the ones who have the expertise. It can be very easy to slip into deferring to the expertise of professionals – even in matters about daily living, understanding the effects of medical drugs or the impact of illness on family life. These are the kinds of areas where consumers and carers do know more than clinicians.

It is particularly easy to defer to the expertise of clinicians in situations where they clearly exert more power than either consumers or carers. Some people want to please the clinicians with whom they must work quite intimately. Many people do not want to test the boundaries of a relationship upon which they feel dependent. Even politically experienced consumers find that, while they can be very strong and confident in all kinds of advocacy roles, they tend to adopt a far less assertive persona with their ‘own’ clinician.

It is important to realise that **different clinicians have different views, attitudes and styles**. Some need to remain in control and in command. Without the deference of their patients/clients they might feel threatened, and so they use their power (and sometimes their charisma) to reinforce existing deferential relationships. Other clinicians value independent client decision making. They try to encourage consumers and carers to make their own decisions and to live with the consequence of these decisions.

Encouragement and recognition of your expertise by your clinician and by others can help you to recognise your own strengths and wisdom. But remember: **your clinician cannot give you the power of self-determination. You must find that for yourself.**
Reflect on your own expertise

When you as a consumer/carer are asked to sit on committees, give talks, write papers and other activities, it is useful, as part of your preparation, to reflect on your own expertise.

- It may seem easier to open a presentation by saying, ‘I don’t really know anything about this but . . .’, thinking that such tactics can atone for hesitations or deflect criticism. The unfortunate reality of opening with this kind of self-criticism is that it undermines the seriousness and importance of your expert contribution. So don’t put yourself down.

- In a similar way, consumers and carers have been known to introduce themselves at meetings as ‘just a carer’ or ‘just a consumer’. This undermines and undervalues their own input and, even more importantly, undermines and undervalues the input of others who name themselves as consumers or carers.

One of the first things that many active consumers and carers notice when working on committees, advisory groups and so on is that much of what they see and hear around them is, in fact, mere bravado. People who are experienced in public forums have learnt many tricks and it is useful to watch experienced ‘players’ at work. How have they organised their material? How often do they speak? Have they really read all the material that was sent out before the meeting?

Don’t punish yourself

A lot of what makes people look effective and in control is just that they are comfortable and ‘at home’ in a given situation. The same people who seem so admirably competent in the meeting room might be completely useless at various other activities with which they are unfamiliar. If you feel that you are not coping very well at first, try to stick with it. As you become used to the various procedures and mechanisms you will also become more confident in your abilities.

Clearly some consumers and carers will not want to participate in particular kinds of activities. It is very important that you do not allow yourself to undertake tasks that are so harrowing to you that they cause unnecessary distress. You may never feel comfortable telling your personal story in public, or sitting on a decision-making committee or working as an educator of service providers. This does not mean that you are without expertise – many so-called experts avoid tasks that make them feel uncomfortable. Consumers and carers, like the rest of the population, have their individual strengths and weaknesses. Build on your strengths and do not punish yourself for being human.
3.10 Note-taking and minute-taking

This is a very useful skill which can be applied to many activities. Perhaps the most common form of note-taking that members of groups will find themselves involved in is taking minutes, so this is covered in some depth here. Generally though, there are some principles of note-taking that can be quite helpful across a variety of situations.

Note-taking

People are often seen busily taking notes at lectures, conferences, seminars and meetings. Unfortunately, quite often these notes turn out to be fairly meaningless because the person misses out on the deeper message that is being put across and fails to understand its meaning. If it’s not necessary to reproduce the dialogue of a speaker, as in minute-taking, intense listening is often better than furious note-taking. (Also see 1.6: Interpersonal communication.)

Problems which result from furious note-taking can include:

- Not being able to read the notes – writing so fast they are illegible,
- Not being able to understand the notes – everything the speaker said has been written down, but what does it all mean?
- Failure to see the body language of the speaker – this can be a story in itself,
- Failure to note voice inflections the speaker uses to emphasise points,
- Failure to grasp the deep meaning of the talk.

These problems can be overcome by:

- Listening intently to the message which is being put across and making sense of it as you listen.
- Asking the speaker for clarification on unclear messages.
- Looking at the speaker to catch his/her body language.
- Taking notes of key concepts and ideas.
- Noting down names of people the speaker often refers to.
- Making notes on the inflections used at certain points.
- Taking notes in a way that makes sense to you – it doesn’t have to make sense to anyone else. Unless you have shorthand skills, develop your own style – some people find diagrams are better than words.
- Using word pictures as memory aids.
- Not getting concerned if you miss something you think is important – you may be able to later ask the speaker for clarification.
Minute-taking

Anyone who has had involvement in committees or workshop groups may remember numerous times a stony silence following the question, ‘Who would like to take the minutes?’ There’s never a rush of people saying, ‘Me, me, I’ll do it’. Taking minutes for the first time can be a nervewracking experience as the following scenario demonstrates.

A matter of simple minute-taking!

John is a new member of the Springfield consumer action group, is very keen and attends every meeting. The day before the next meeting he is approached by the group chairperson: ‘John, our regular minute-taker has to withdraw from the group for a while. We’re in desperate need of someone to take the minutes. You say you’re keen to have some more involvement, so I wonder if you can take the minutes at the meetings. It’s quite simple. It’s only a matter of simple note-taking. I’m sure you can do it very easily’.

John shakes his head, but hears himself saying, ‘Yes, no worries I can do that’.

‘Thanks’, says the Chairperson, ‘see you tomorrow night then’, and walks off.

John quickly finds a seat (so that he doesn’t fall on the floor). Minutes? John has never taken a minute in his life. He has seen others doing it at meetings, and he has seen people taking notes at seminars and conferences, but he has always been too interested in the actual proceedings to take any notice of what the minute-taker was doing.

John looks around for some information on minute-taking, but can’t find anything. He asks some of the other group members – they all seem very uncomfortable with the subject and are not much help. He is aware that minutes are a record of what happens at a meeting. Questions are swimming around his head, ‘Should everything that is said go into the minutes? If not, what goes in and what doesn’t and how do I decide quickly at the time?’.

John has some doubts over his minute-taking skills, ‘How can I possibly write quickly enough to keep up with what people are saying? Will I be able to read and make sense of what I have written afterwards? Oh, why did I volunteer to do the minutes?’.
**What are minutes?**

Minutes are a summary of the following facts:
- Time and date of a meeting and where it is held,
- Names of all people present, and apologies for those who were expected but did not attend,
- All items discussed, whether on the agenda or not,
- Any actions agreed upon, and the names of the people responsible for carrying out those actions,
- Date for completion of tasks and actions.

**Before the meeting**

- Make sure that you have plenty of paper to write on – it’s a good idea to have an notepad which can be used solely for taking minutes,
- Make sure you have two or three pens,
- Have a look at the agenda headings and prepare headings for the minutes from the agenda,
- As the people attending the meeting take their seats, start to write down their names under the ‘Attendance’ heading.

**During the meeting**

- Sit in a position where you will be able to hear everybody clearly, but where you won’t be ‘in the middle of it all’.
- Don’t try to write a verbatim (word-for-word) record of what people say – you won’t be able to keep up. Focus on writing the **facts or ideas** in a way that gives you an understanding of what is said.
- Discuss with the chairperson the need for her/him to summarise for you and give you time to write.
- Don’t allow yourself to be ‘involved’ with the discussion.
- Record too much rather than too little.
- Record the names of all the people present at the meeting.
- Record the time the meeting begins.
- If you can’t hear or understand any speaker, ask them to repeat or clarify what they say. Read what you have written so that there can be no disagreement later as to its accuracy.
- Record late arrivals and early departures.
- Record what happens, even if it is not in the order listed on the agenda.
- Record the name of the proposer and the seconder of any formal motions.
• If somebody has a minority view and asks for that to be ‘noted in the minutes’, take down what is said and read it aloud so that all present can agree that it is what the person is saying.

• Make sure that any action to be taken before the next meeting is given a ‘time to be completed’, and that there is no confusion about what is to be done, by whom, and by when.

• Note the time of breaks for cigarettes, refreshments or other reasons, and when the meeting resumes.

• Note the time the meeting ends.

**Ease into taking minutes**

Perhaps the best way to learn to take minutes is to sit next to the person who is taking the minutes and gradually take over the role as skills and confidence are gained. If, like John in the example, you are asked to take minutes when you feel you are not ready, be assertive and say you are prepared to, but only after you have learnt the skills by sitting in with someone else a few times.

**References**

3.10 Note-taking and minute-taking
Many forms of advocacy involve groups and organisations. This section of the Kit focuses on skills and strategies which promote equality and empowerment within the group – starting up, keeping going and staying effective.
One of the reasons that individuals and groups achieve success is that they are focused. First they establish a process that enables them to become focused. This is done by agreeing on the mission statement, defining the guiding principles and developing an operational plan to implement them. By having these in place, the individual or group can then focus on achieving goals by following the plan. As skills in developing these principles and structures are discussed elsewhere (also see 4.3: Developing your group), this section assumes that these structures are in place, and deals with skills useful in maintaining focus on specific issues.

**Funnelling and brainstorming**

Many people within a group have many good ideas which are beneficial to the development of the group as well as to its work. One way to obtain these ideas from people is through an exercise in ‘funnelling’. As the name suggests, funnelling involves turning lots of ideas into a few very high quality ideas that can be put into action. Funnelling is conducted with the process of ‘brainstorming’, which is where group members put forward their ideas, no matter how weird or impractical they appear to be. This process can be adapted for use by groups, large or small, or by committees.

**Funnelling and brainstorming exercise**

**Purpose:** To identify and prioritise lists of needs, concerns, opinions or observations group members have in regard to a specific issue.

**Duration:** 15 to 35 minutes.

**Materials needed:** Large sheets of paper (such as butchers paper) to put up on the wall, something to attach the paper to the wall (blu-tack), some marker pens, paper and pens for each small group.

**Leadership:** The process needs to be led by someone: a group member, possibly from the committee, or a facilitator invited from outside the group (for this example a facilitator is used).

Box continues on the next page
Process:

1. **Decide which issue** is to be brainstormed.

2. **Divide into small groups** of three to five people, with each group nominating a brainstorm note-taker.

3. **Generate ideas.** The facilitator directs each group to brainstorm as many ideas as they can on the issue in a specific period of time (say, 10 minutes). This is not the time to evaluate ideas. All ideas get written down by the note-taker. No one judges or comments on the contribution of others until all the contributions are recorded. It is this process of having the opportunity to speak without fear of contradiction or interruption, and to express all manner of ideas, that makes brainstorming an effective strategy for providing innovative ideas.

4. **Prioritise the ideas.** The facilitator asks each group to take no more than five minutes to choose three or four **best ideas** from the list generated.

5. **Collect the ideas from each group.** The facilitator asks a group for one of their top three ideas and records it on the large sheet of paper attached to the wall. This is repeated for all the groups, with subsequent groups being asked to provide ideas that have not already been recorded.

6. **Present the results.** The main sheet of paper represents the overall group’s top priorities on the issue in question.

Summarising and clarifying

Another method for both individuals and groups to use to focus on a specific issue is through the processes of summarising and clarifying. While the following example applies to a group, it can be equally useful to an individual.

**Example Scenario:**

Members of a particular group are concerned because several consumers have been refused admission to the local psychiatric inpatient ward because, ‘their behaviour in the past has been considered unacceptable by the director’. Members in the group are furious and there are many suggestions about what the group should do about the situation.

**Step 1: Define the issue**

*In this step the specific issue must be clearly defined in only one or two short sentences, for instance:*

‘In the last two months, three consumers have been denied inpatient treatment at the Springfield hospital, despite having the appropriate referrals from their psychiatrists and recommendations from their case managers.’

Box continues on the next page
Step 2: State why the issue is important
‘The issue is important because one of the main aims of the group is to provide assistance to consumers in obtaining appropriate treatment in accordance with the National Standards for Mental Health Services.’

Step 3: What are the facts or beliefs about the issue?
‘The reason given in all three situations was that admission was being denied because the past behaviour of each individual was not acceptable. Hospital staff did not deny that the consumers required assistance. As this particular hospital is the only one with an appropriate inpatient facility, staff denied these people the care that their psychiatrists and case managers believed they should receive.’

Step 4: What does the group want to see happen?
‘The group wants to set up a meeting between members of the group, the director of the inpatient ward, the three consumers involved, their psychiatrists and case managers to discuss admission procedures and the need to work towards achieving the National Standards for Mental Health Services.’

Step 5: What positive results can this achieve?
‘Procedures can be developed so that the inpatient ward is truly accessible to people when they really need it the most, which can prevent a lot of suffering on the part of the consumer being denied assistance as well as family and friends. The local mental health service can also be further advanced in conforming to the National Standards for Mental Health Services.’

The above scenario is just an example of how a process of summarising and clarifying can be used to maintain a focus on the issue. The group didn’t get side-tracked into laying blame on any specific person, or into any of the many side issues that can be discussed in such a scenario. By focusing on what occurred and the known rights of people, the group has a strong case. If the director refuses to attend such a meeting, the group can choose to escalate the issue to involve others, such as taking the issue to the public via the media.

The process above involves the whole group, led by the group leader. In some situations, such as the funnelling and brainstorming example above, it may be beneficial to have an external facilitator, as many members, including the leader, may be very emotional and angry in regard to the specific issue.

As a tool for groups or individuals to use, the steps in the above scenario are set out on the following page, with space for the issue and responses to be written down.

References
National Standards for Mental Health Services (1996), Australian Government Publishing Service, Canberra
Focusing on the issue

Define the issue (in one or two sentences)
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4.2 Starting up a group

There are various ways of starting up a group, and various models from which to take guidance. This section can’t go into all these different models, but it can look at one way of starting up a group which has proved to be very successful. One process, which received endorsement by Consumer Health Advocacy (Queensland) as a model of ‘best practice’, was developed and used by the Queensland Mental Health Consumer Participation Project. This model is grounded in social justice philosophy, but focuses on sound group development principles with the concept of empowerment as its core.

The birth of a group

Groups can come together through a number of ways. People interested in a certain cause may start meeting together to discuss what action they can take, other people are invited to join over time and a group comes into existence. In these early stages it is a good idea to pay attention to issues which may have an impact on the group in the future.

One of these is the issue of representativeness. This refers to the group’s ability to represent those whom it claims to represent (if it claims to represent anyone). Groups don’t necessarily have to claim to represent anyone else and can say that, ‘this position represents the views of members of this group’ and that’s it. However, a group which conducts advocacy and/or community development can be challenged to demonstrate how it can speak on behalf of other consumers or carers. If the group consists of 10 like-minded people who have never consulted with the broader community of consumers and carers, it may have difficulty in demonstrating its representativeness. As a result, the group may not have much credibility, and may have trouble in attracting funding.

It needs to be made clear that, no matter how hard a group tries, it can never claim to be truly representative. There is always a wide diversity of opinions. However, groups do need to strive to be as representative as possible. One way to begin is to hold widely advertised public forums and to invite all interested people (that is, potential group members) to attend.

Public forums

Purposes of a public forum

- To provide an opportunity for all ‘eligible’ and potential members to have a say in how the group will form,
- To explain ‘what it’s all about’ – why the group is forming,
- To invite people to join the group.
Planning the forum
Perhaps the first thing that has to be done is to consider and define who is ‘eligible’ to be a member. A consumer peer advocacy group may only want consumers as members. A decision needs to be made on defining ‘who is a consumer’ for the purposes of the group. It’s a good idea to allow for flexibility at this stage when ‘the group’ consists of a few individuals. It’s quite likely that, down the track, when the group is operating in a democratic and empowering way, newer members may have different ideas on who is eligible to be a member. However, a start has to be made somewhere.

- **Find an organisation to sponsor the public forum**, if possible. There are some costs involved, such as refreshments (possibly lunch), publicity including production and copying of flyers, postage of some letters and making some telephone calls. If transport can be provided, or access to the venue is explained clearly, then more people can have the opportunity to attend. Some mental health community organisations, or generic community and neighbourhood agencies, may be a place to start.

- **Make a list of names and addresses of individuals and groups** that you believe may be interested in attending the forum, or other relevant contacts who can promote it.

- **Consider having an external facilitator** (someone has skills in facilitating meetings and forums, but is not eligible to join the group). A person from an existing organisation may agree to act as facilitator. Support, advise and fully brief the facilitator before the forum.

- **Find an appropriate venue to hold the forum**. Think about:
  - Is the venue close to public transport?
  - Is it appropriate for the people attending? (For instance, can people smoke?)
  - Is the venue free? (Many community organisations offer free venues.)

- **Set a date for the forum**. Think about:
  - Allow plenty of time for people to make arrangements to attend,
  - Consider the best time and day that is likely to suit the people attending,
  - Make sure the date doesn’t clash with other things happening on or close to that day.

- **Arrange publicity for the forum**. Think about:
  - Develop a flyer advertising the forum.
  - Distribute the flyer everywhere eligible members may come into contact with it, for example, consumer and carer groups, mental health groups, mental health services. Ask others to distribute the flyer.
  - Send personal letters to leaders of various appropriate organisations, advising them of the forum.
  - Put an advertisement or community announcement in local community newspapers.
  - Request the local radio to make a free announcement about the forum.
Plan the actual forum. Think about:
- What are the aims/hopes for the day?
- Who will facilitate?
- Who will be the key speakers; how much time should each be given; how much discussion will be useful?
- How long will it last? (Four hours should be the maximum time.)
- What needs to be finalised at the forum?

Develop an agenda for the forum:
- In developing the agenda, calculate for the forum to last no more than three or four hours,
- Keep the agenda limited to fulfilling the aims and purposes of the forum.

Make arrangements for catering. You can keep it simple by providing just tea, coffee and some biscuits. Alternatively, try to find a sponsor to cover the costs of more lavish catering, such as a barbecue.

Conducting the forum
- Consider putting up some signs to direct people to the forum,
- Have someone greet people, make them feel welcome and direct them to refreshments and seating,
- Conduct the forum as set out in the agenda – a good facilitator limits discussion to the times allocated on the agenda.
- Make sure that vital information is obtained and communicated to all:
  - Names and addresses of people wanting to join the group,
  - The venue for the follow-up meeting of the group,
  - The date and time of the meeting,
  - Foreshadow one or two items for the agenda of the first meeting.

The first meeting
The public forum has been held, and the group is confident that as many interested and eligible people as possible are included. The next step is to have the first meeting.

People are likely to come to the first meeting with a wide range of expectations of what the group is all about. Those who initiated the whole idea in the first place may have certain ideas about the role and functions of the group, and these may be different from the views of the ‘new’ members. In order to provide some clarity, it is a good idea to stick to the process and business of ‘forming a group’ before getting ‘down to business’.

Some groups do immediately get stuck into the issues. This is very understandable as many people have burning issues which they want to start working on straight away. Unfortunately, most of these groups fail, because they don’t have any underlying structure.

All effort must initially go towards STARTING THE GROUP.
The need for structure

Many people have found that groups that succeed in keeping their members and achieve their goals are those that have developed structure. Janet Meagher completed a Churchill Fellowship study, investigating empowerment and self advocacy models in Britain, Canada and the United States. She found that the most common cause of failure of mental health consumer groups was lack of structure of the group. According to Janet:

‘A very common element in fledging consumer groups is the almost obsessive determination to avoid a formal structure. Each group that started in this way either inevitably changed direction, added some protective structure or faltered. I did not see any successful unstructured groups.’

Structure begins with some principles and guidelines about what the group will do and how it will do it. Some of the questions which need answers include:

- What functions will the group undertake?
- What operating guidelines will the group have?
- What strategies will the group use to achieve its functions?
- How will the group elect people to carry out specific functions (for example, a committee)?

These questions (and more) are answered in 4.3: Developing your group.

References


4.3 Developing your group

In 4.2: Starting up a group, a process is suggested based on the need for structure. Before continuing, readers are advised to review that section.

Introduction

Many groups develop according to social justice principles, showing a lot of grit and determination to bring about social change. Unfortunately, this alone is not helpful to the new group. Without any structure supporting it, the immense barriers to social justice become evident as soon as the group begins to work on its goals.

While the principles and structures suggested here are underpinned by the value of empowerment and social justice, they also reflect an organisational development framework. The development of a group is a process, subject to all the dynamics that are common to achieving cohesive work teams, and subject to the stages of group development that are experienced by all groups over time. (Also see 4.5: Team development.)

Focusing on organisational group development means putting the goals (often referred to as content) to one side for the short term and concentrating on building up the structure of the group. This takes time, but it means that the group will be long-lasting. Below are some key assumptions about the process of group development.

Group development

- Groups go through stages of development. These stages are identical with those experienced in all small groups. They move from an initial stage of ‘leader’ dependency, where the group cannot survive without a particular person (or people) providing direction and leadership, through to a stage of ‘independence’ where the group is self-managing. In other words, if the leader leaves there are several people capable of taking on that role.
- At each stage the group is faced with dynamics typical of that stage. If the group does not resolve the conflicts typical of that stage, it collapses or remain stucks there.
- When the stages of group development are successfully negotiated, the group reaches a stage of cohesiveness.
- All groups are assisted by guidance, facilitation and training to move through the growth stages.
Stages of group development
Some of the stages that groups go through include:
- Groups that just started are at the stage of resolving the types of conflicts that arise within any new group, such as: eligibility for membership; building up membership numbers; getting members to participate in discussions; trying to agree on common goals and ways to achieve the goals,
- Groups that have reached the ‘norming and storming’ group development stages, with conflicts over power and control,
- Groups that have existed for several years and want to re-structure in order to improve their effectiveness,
- Groups that have reached a relatively high state of functioning and empowerment.

The first meeting
A public forum has been held. A group of interested people arrange a time, date and place for the first meeting.

A question of leadership
At the first meeting, someone needs to take a leadership role. Someone needs to chair the meeting. Someone needs to take notes of the meeting. Who is going to do this when no one has yet been voted in as a leader? After all, this is a democratic group based on empowerment – surely someone can’t just step onto the ‘throne’. This is a very important, and delicate, time for the group. The person most likely to take on this initial leadership role is one of the people behind the formation of the group in the first place.

The first meeting is not the time to elect the leader and committee members.
One solution around this dilemma is to appoint an interim chairperson and committee and set a firm date to hold the first annual election. A mistake many groups make (including sporting and social groups), is to immediately appoint its leaders. If the leaders turn out to be inappropriate (they may be real dictators), it is very difficult to get rid of them, and the group may have to put up with them for a whole year before the next election comes around. In the meantime, half the members of the group may leave because of the turmoil. It’s better to make a decision on who will be the acting leaders for the first three months, when a meeting can be held to elect leaders for the next year.

Other issues for the first meeting
Other issues which need to be decided at the first meeting include:
- Venue for future meetings,
- Time and day of meetings suitable to most participants,
- Transportation,
- Catering,
- Distribution of members’ contact details,
- An agenda for the next meeting.
Developing a plan

Having elected someone temporarily to the role of chairperson, and perhaps someone else to take the minutes (or at least notes) of the meeting, the group can proceed with developing a mission statement and some principles. This probably occurs at the second meeting, as the first is taken up with the leadership and other issues. It is important to devote meetings to only one or two issues at a time.

Developing a group is not too different from developing a business. A business starts off with a business plan. A group also needs the equivalent of a business plan. A plan enables a group to define its purpose, agree on common goals and set up a structure that provides the best opportunity for achieving these goals. The plan may outline the following:

- The vision and the mission of the group,
- What functions the group will undertake,
- How these functions will be produced,
- Who will do the work,
- How the activities of the group will be made known,
- How the activities of the group will be evaluated for effectiveness.

Mission statement

One of the first items of business that can be conducted at the second meeting of the group is to decide on a mission statement. A mission statement is the expression of a common goal or purpose that all members agree on and are committed to. A mission statement is never questioned, even at times of conflict within the group. A mission statement can be one simple statement which succinctly sums up what the group stands for. For example, a mission statement can be based on a definition, such as that of empowerment:

‘To empower and assist people, who have been prevented by socio-economic and political forces from having power and resources, to take charge of their own lives and to have ownership and control over their own destinies.’

This is only an example. What is important is that all members agree on the most appropriate statement for their mission statement.
Guiding principles

Once the mission statement has been decided by the group, the next step is to develop the guiding principles. These comprise several short statements which clearly state what the group intends to do to achieve the mission of the group.

To develop the guiding principles, the members of the group ask themselves questions such as:

- Why is this group being established?
- What function will the group have?
- What is the group’s role?
- What is the group’s purpose?

Defining the functions of the group through the development of guiding principles assists the group in limiting the activities it will undertake to its original purposes. ‘Functions’ should be distinguished from ‘goals’. Functions are categories of activities that the group will engage in. Goals are specific activities that the group wants to achieve. An example of a function may be:

‘To provide advocacy services to people diagnosed with a mental illness.’

It’s a good idea to limit the mission statement to two or three statements. Remember they are only categories of activities. The newly-formed group can devote an entire meeting (meetings are recommended to only run for two or three hours) to establishing the mission statement and guiding principles. A common mistake at meetings is to try to cover too much. (Also see 3.7: Chairing meetings and 3.8: Being a committee member.)

Goals

Once the group decides on a mission statement and guiding principles, it might go on to define the goals which it wants to achieve. An example of a goal may be:

‘To educate mental health professionals in what assists consumers in their recovery process.’

In the beginning, it’s a good idea to limit the goals to those which are achievable in the short term. (Also see 2.2: Identifying and overcoming barriers.) Having success with short-term goals gives all members a morale boost and provides strength for forthcoming battles. Once the group is on a stronger footing, it can develop long-term goals. It’s important for the new group to also limit the number of goals. One or two goals will keep the group busy at this stage when it is also tending to organisational (process) matters.

Once equipped with a mechanism for electing leaders, agreeing on a mission statement, guiding principles and short list of goals, it’s down to business.
A mental health peer advocacy group may develop along the following lines:

- Hold a meeting of several consumers/carers interested in starting a group.
- Consult with existing consumer/carer organisations for advice and assistance.
- Obtain support to enable a forum to be held, notifying consumers/carers who may be interested in attending.
- Hold a forum for consumers only, or carers only, with clear objectives for the forum: determine the purpose of the group; have a registration form for participants to fill out; notify participants where and when the next meeting will be held.
- Focus on group development at initial meetings. Develop a mission statement on how the group is to operate; develop a set of guiding principles for the group; develop a strategic plan to achieve the mission statement; decide who will do what; decide membership issues.
- Do not undertake advocacy until the group has developed a sound structure.
- Start advocacy with one relatively straightforward issue; one that has a good chance of being successful.
- Work on only one issue at a time. See this issue right through to its conclusion before commencing work on another issue.
- Don’t be distracted from pursuing the issue.
- Maintain ‘passion’ – encourage it.
- Network with other groups – enlist their support where appropriate.
- Ensure that all members of the group are involved to the fullest extent in both the development of the group and in the advocacy work being undertaken.
- Consider the social needs of the group – that is, occasionally have some fun.
- Celebrate success and victories, no matter how small.
- Keep recruiting members.

References
Leadership has been identified as one of the most important factors in the success or failure of groups and organisations. Leadership is also strongly related to the group members’ satisfaction with the group. Many writers on the subject of self-help or user-run groups, whether a mental health consumer group or another type of group, stress the vital importance of good leadership. The significance of enthusiasm and persistence in a group leader cannot be overestimated in understanding the development of successful groups.

Attributes of a good leader

Researchers of successful user-run groups also stress the importance of there being a leader who is a founding member with certain attributes. Some of these attributes include:

- Willingness to devote personal time,
- Ability to network successfully with other groups and organisations to recruit membership and/or resources,
- Skill in the development of flyers, brochures and working with the media,
- Ability to locate cost-effective meeting places,
- Skill in group process development,
- Skill in providing effective feedback to group members and others,
- Ability to be flexible and tolerant of a diversity of opinions,
- Ability to create an atmosphere of partnership and encourage members in active participation,
- Ability to be a facilitator of empowerment,
- Capacity to surrender control of the group as the group process evolves.

Of all the skills and attributes listed above, perhaps the most important of them all are the last three. If a leader cannot, or does not, enable the group to become empowered, then the group is not really a group, but an individual with a bunch of followers. Further, if a leader cannot, or does not, allow other group members to have power and take control, those members can become disillusioned, resentful, disempowered and leave the group.

Janet Meagher, who completed a Churchill Fellowship study of mental health consumer groups in a number of countries, highlights these last three attributes as being the most important for consumer groups. It may appear that a dominating, charismatic and highly motivated consumer can make a perfect leader. This person gets in, does the work and becomes quite indispensable. The problems occur when the group starts relying heavily on this person and passes over the entire management, leadership and direction of the group. Firstly, this is disempowering for the other group members who
do not get the opportunity to learn and experience these tasks. Secondly, the leader can burn out and leave the group, which is, in effect, disempowered and completely unprepared for the tasks lying ahead.

A good leader is always working on developing the group to the stage where the group can operate without that particular leader. To some extent then, the leadership style needs to reflect the group’s current stage of development.

**Leaders and stages of group development**

There are many types of group/leadership dynamics that are most suitable for specific situations. For example, the dynamics between a group of mountaineers climbing Mt Everest and their leader is quite different from the dynamics between a community advocacy group and its leader. The following are a particular sample of group/leadership dynamics that are appropriate and relevant for community groups which focus on empowerment:

1. In the initial stage of group development there is a high reliance on the leader for direction and empowerment,
2. As the group develops and becomes stable, the confidence and skills of the membership increases with direction from the leader,
3. As the skills and motivation of members increase there is less need for the leader to be directive and they can concentrate on being supportive,
4. Members are now confident, skilled and self-directing and have less need for a defined leadership role.

**Effective leadership**

Being an effective leader is all about power: how to use power and how to share power. The skills required to be an effective leader are the skills required to appropriately use power. In relation to individuals, power can be defined as the ability or potential of an individual to influence other individuals. Some leaders (such as Adolf Hitler) had power by using force to influence individuals. Other leaders (Mother Theresa) had power by gaining respect to influence people.
Five leadership styles

1. You solve the problem or make the decision yourself, using information available to you at the time.

2. You obtain the necessary information from other group members, then decide the solution to the problem yourself. The role played by group members in the decision-making process is in providing the necessary information to you, rather than generating or evaluating alternative solutions.

3. You share the problem with relevant group members individually, getting their ideas and suggestions without bringing them together as a group. Then you make the decision, which may or may not reflect your colleagues’ influence.

4. You share the problem with members as a group, obtaining their collective ideas and suggestions. Then you make the decision which may or may not reflect your colleagues’ influence.

5. You share the problem with the members as a group. Together, you generate and evaluate alternatives and attempt to reach agreement (consensus) on a solution. Your role is much like that of a chairperson. You do not try to influence the group to adopt ‘your’ solution, and you are willing to accept and implement any solution that has the support of the whole group.

Adapted from Yetton (1984)

For community groups, especially user-run groups, the fifth style of leadership shown above is the most appropriate. This type of leadership can also be called facilitative leadership as it facilitates the empowerment of the group. Perhaps the most persistent and thoroughly demonstrated difference between successful and unsuccessful leadership can be seen in the sharing of the leadership function. Generally, those groups and organisations in which influence is widely shared are the most successful. No doubt this is due to the increased motivation and commitment that individual members display when empowered and involved in decision-making.

Such involvement itself fulfils the need for participation and autonomy that all people have, and so democratic groups and organisations have a built-in reward system for member participation. Not only will members want to stay with the group, but the number of people wanting to join the group is likely to increase as people hear about the rewards coming from participation. Wide sharing of leadership functions also means a more effective organisation because better decisions are made if a number of people are contributing their experience and skills rather than just one or two. Leadership sharing also ensures continuation of the group if the leader leaves the group.
Feedback

If it is agreed, as discussed above, that the kind of leadership most suitable for a service-user group is democratic, or facilitative, leadership, then a close look at developing the skills of providing feedback is needed. Feedback is one of the most important skills for the facilitative leader because, whether they realise it or not, leaders are constantly providing feedback. How this feedback is provided is the difference between good and bad leadership. As many of the skills required for effective leadership are covered in other sections of this Kit, the focus here is on skills and strategies for providing appropriate and effective feedback.

There are four types of feedback which leaders of groups and organisations may use:

**Silence:** This is where no response is given. Some leaders deliberately use silence to get the person they are communicating with to ‘spill their guts’. It is, however, a derogatory and potentially damaging approach and has the following impacts on the member:
- Decreases confidence,
- Reduces performance,
- Creates confusion – ‘Am I doing good work or not?’

**Criticism:** Criticism is a negative feedback which identifies behaviours or results the leader believes are undesirable or not up to standard. An example is, ‘That last newsletter you edited was complete rubbish’. Of course the purpose of the feedback is to stop the undesirable behaviour, but the actual impact on the receiver is more likely to:
- Generate excuses and blame others,
- Decrease confidence,
- Lead to avoidance behaviour – What’s the point of trying?’
- Damage relationships within the group,
- Eliminate other related behaviours, which may in fact be positive – I don’t want to do this anymore – do it yourself’.

**Advice:** Giving advice can identify behaviours or results that are highly regarded and often specifies how to incorporate these in future work. An example may be: ‘Remember to ask everybody at the meeting tonight to contribute a few paragraphs on the activities they are involved in so that the next newsletter informs the readers what the group is currently doing’. The purpose of this approach is to shape or change behaviour to increase performance. The impact of this approach on the member is to:
- Improve confidence,
- Improve relationships,
- Increase performance.
Reinforcement: Positive reinforcement identifies behaviour or results that are desired, taking into consideration the level of experience of the person. An example may be: ‘The standard of the newsletter ensures that the community awareness work the group is undertaking is broadly communicated to all the stakeholders. Thanks for all your time and effort, you’ve done a really good job’. This approach must be genuine and should not be used if it is not true or if what is said is not really believed. That is tokenism and is ultimately extremely damaging. The purpose is to increase the good work the person is doing. The impact on the receiver on hearing such feedback is to:

- Increase confidence,
- Increase performance,
- Increase motivation.

Effective feedback

Below are just a few examples of how to provide effective feedback. To develop this further, try thinking of other ways effective feedback can be provided.

Check to make sure that clear communication has occurred

Good: ‘Before we go into the meeting, let’s run through the main points that we want to cover again.’

Bad: ‘Okay, let’s go; everyone knows what we want from the meeting.’

Clearly state the impact on the group

Good: ‘John, when you don’t show up at the workshops we have organised with the university it makes the group look disorganised and it may jeopardise future workshops. Is there some way I can help to ensure that you get to the workshops?’

Bad: ‘Because you didn’t show up at the workshop, John, we may not get another opportunity. I hope you’re satisfied.’

Make sure that the feedback is specifically related to behaviour

Good: ‘Ruth, you haven’t attended the last three committee meetings. Are you having some problems getting to the meetings? Perhaps you want to discuss this.’

Bad: ‘Ruth, because you can’t be bothered to come to meetings, everyone else is getting annoyed with you.’

Always genuinely attempt to improve the situation

Good: ‘Chris, I know how you like to get the newsletter just right, and I know that you’re under a lot of pressure at the moment. I will help you edit it this time but, as my time is also valuable, I really want you to take that newsletter publishing course so you can develop your skills and be confident of doing it yourself in the future.’

Bad: ‘Chris, you always need help with the editing. Why should I help you – it’s not my responsibility. Don’t you think it’s time you learned how to edit the newsletter yourself?’
Points to remember when giving feedback

1. Reinforcement is the most effective form of feedback.
2. Criticism is the most ineffective form of feedback.
3. The difference between criticism and advice is the way it is given and the consideration to timing and circumstances.
4. When feedback is mixed (for example, ‘What a good job you’ve done, it’s just a pity the last article is a bit confused’), the impact is diluted and, worse, the member may end up confused and not know what to do in the future.
5. Criticism overpowers all other feedback (see point 4 above).
6. Silence is not appropriate – it can be, and generally is, interpreted in more than one way.

Conclusion

A title doesn’t make a leader. Just because someone is given authority doesn’t mean that the person has, or can use, authority. Real leadership is earned. A person earns the status as a leader by the way he or she acts in the group.

This section has taken a broad look at the skills involved in leadership of a user-run group and has provided information on only a few of the skills required for effective leadership. Many of the sections in this Kit also refer to aspects of leadership.

References


Team development

Individuals within groups often have a lot of experience, passion, skills and enthusiasm. Group members can encourage a cohesive group by reminding each other to focus on their commonalties, strengths and shared purpose. In all groups, whether sporting groups or national organisations, problems can arise when individuals join with others to produce a team effort. If the group is new and the individuals don’t know each other particularly well, they can keep their knowledge and skills to themselves, preferring to just do the bit of work which they can take individual credit for.

Often in a new group, individuals may not at first like each other and may try to keep a distance from each other. While this may seem to be a good personal strategy, it’s not good for group cohesion and performance of the group will suffer. Groups that are successful in their work and develop sound group structures have good teamwork. The following skills provide a basis for effective team development. Many other skills in this Kit also relate to team development and the reader can skim through the index to identify and follow them up.

Four preconditions for team effectiveness

1. Mutual need – Group members acknowledge that they need each other.
2. Joint commitment – Group members make a commitment to work positively with each other to achieve team effectiveness rather than being sunk in resignation or resistance.
3. Declaration of purpose – There is a clearly understood statement of the group’s reason for being.
4. Accountability – So group members are clear who is responsible for a given task, one person only is given the task with a completion date. This person may not necessarily carry out the task, but is responsible for making sure that it gets done.

Teams go through stages, not unlike groups and organisations. When teams first get together they need a high level of vision and direction from the team leader. This is often followed by a period where dissatisfaction and complaints within the team are common, until the team works through these issues and becomes a productive team.
Managing the team’s process

When members of the team first get together to talk, it’s a good idea to examine two components of the discussion: the substance of the discussion and the process of the discussion. The substance of a discussion is the actual content or agenda. While the content is important, how issues are discussed must be considered. In other words, what is the team’s process?

Every group has two kinds of process issues to manage: task-process issues and people-process issues. Task-process involves the relationship between team members and their work. People-process involves the relationships of team members to each other. Both issues are equally important. Almost all of the problems encountered by teams can be tracked to poor processing, because the group’s output depends on its productivity and cohesiveness. Both are affected by group process.

Establishing clear ground rules

Establishing the ground rules and abiding by them ensures a productive and cohesive team. Applying the ground rules in team problem solving and decision making increases effectiveness and saves a great deal of time. Below are some suggestions to use as a guide in the establishment of the team’s ground rules. The ground rules in themselves are not as important as the ideas they represent for the team’s effective functioning.

Task-process ground rules

- **Clarify team activities and specify the outcomes:**
  Never assume that team members understand the purpose of problem-solving or decision-making meetings. You can never be too obvious or explicit about a desired outcome.

- **Seek alternative methods and procedures for achieving outcomes:**
  Be flexible and creative in the way the group performs its tasks. Methods used in solving one type of problem may not be suitable for solving another type.

- **Ensure that the task structure is clear:**
  The task structure is the team’s plan for solving a problem or arriving at a decision and includes a step-by-step process to follow in accomplishing a specific task. The team first gains consensus about the steps to follow, then writes them down. This helps the team stay on track. The task structure can be changed from time-to-time, with steps being added or deleted when necessary.
Stick to the subject:
Just as the team must stay on track with the steps in the task structure, it must maintain focus on the subject at hand. When people work together on projects their attention spans can be quite short. It’s easy for conversations to drift all over the place. Whenever individuals in the team think that the conversation has gone off at a tangent they should, using good humour and tact, question the team on how the conversation relates to the agenda and the issues under discussion.

Summarise:
Team discussions can cover a lot of ground and, at the end, members can feel quite confused with what has actually occurred. Summarising from time to time gives clarity to the discussion and assists in keeping to the agenda, as well as providing a concise record of the discussion.

Monitor the time:
Time can quickly get away, especially if there are controversial topics to discuss. It’s a good idea when planning task structure to include a time structure to indicate where the discussion should be at a given time.

Identify task assignments and the ‘next steps’:
At the end of the team meeting, each team member needs to provide verbal commitments on the follow-up tasks they are responsible for. The team also needs to clarify what the next steps are for the team as a whole. Each team member needs to be able to go away feeling equally clear about where the team is at in relation to the issues at hand.

People-process ground rules:
People-process ground rules involve the team members’ relationships with each other. While the team cannot make hard and fast rules for the way members treat each other, expectations can be established and ground rules for agreeable behaviour adopted. While these need to be formulated by the group through consensus, the following examples may be useful for consideration:

- Provide opportunities for everyone to contribute,
- Separate content from personalities,
- Protect team members from personal attack,
- Discuss and reconcile misunderstandings and disagreement,
- Provide a fair hearing for all ideas and comments,
- Provide recognition for the group process.

These ground rules are examples only, and there are sure to be others that teams feel they need to adopt. However, teams do need to agree on the importance of ground rules to work together and on which ground rules to follow. They need to be stated clearly and provided to all team members so there can be no doubt about what is expected from all of them. Ground rules also help those who are considering joining a team to decide whether or not it is for them. They also help new members fit into the team by providing them with clear information on ‘what goes’ and ‘what doesn’t go’ within the team.
Some of the ground rules above are also discussed in the section 3.7: Chairing meetings and 3.8: Being a committee member, and the reader is referred to these sections for additional information.

Team development also requires many other skills. The following essential skills, and many other useful skills, are also in this Kit:
1.3: Assertiveness
1.6: Interpersonal communication
1.7: How to influence people
1.12: Conflict resolution/mediation/complaints
4.4: Leadership
Gino becomes involved in the process

Gino is a consumer of a rehabilitation service. He is asked by the manager of the service to be part of the selection panel for recruitment of a new worker. Gino has never been involved in anything like this before and has some apprehension. However, he is committed to ensuring that a consumer perspective is included in worker selection and wants to gain from the experience.

The manager of the service gives Gino the date and time of the interviews and Gino arrives. As well as the manager, there is one other person there, a worker from the service. The three people talk briefly about the job and the sort of questions to ask the applicants and Gino is given a list of questions to ask. He doesn’t participate much in the discussion because the other two people seem to have more information than he does and he feels a bit confused.

As each applicant goes through the interview process, Gino asks his questions, noting the response and thanking the applicants. He is bewildered that every time he finishes his questioning the manager then asks some questions of the applicant that sound very similar to his own. He begins to wonder if his questions are good enough.

When all the applicants have been interviewed, the manager asks Gino and the worker for their views about each of the applicants. Gino has heard the answers to his questions and has noted them but feels unable to offer much constructive comment because he doesn’t really understand the questions himself. They weren’t his questions, they were somebody else’s. Some of the questions the other two people asked were good but he is not sure if he is supposed to comment on the answers to these. Gino senses he is being encouraged by the manager to contribute and so he makes whatever affirming statements he can: ‘Yes, I think she is really good’. Gino feels uncomfortable. One of the applicants is selected to be appointed to the position. Gino is satisfied that she can do the job. The manager thanks Gino: ‘It’s always great to have a consumer perspective’.

Gino vows that a consumer must never be put in such a position again. He gets himself selected as a member of the service’s policy and procedures committee. His central theme is to ensure that a consumer is involved in every aspect of the process of worker selection and recruitment.
What is the job?

Start by writing out what the job is about
Do this in a team of people who know what the job is supposed to be about. It may be new work or it may be replacing someone who has left a position.

The nature of the work can change over time. Consider whether this is a good opportunity to review an old position to see if the way it is described is still relevant to the work to be undertaken.

Consider the central responsibility of the job
While a job will have many duties to perform, they will all support the core work of the position. Create an action statement about what the job is to achieve, for example, ‘To provide support to...’; ‘To manage...’. This statement will form the position objective.

Create a title for the position
Often the position objective will make the title of the position obvious. On other occasions the title may be decided before the position objective is spelled out. Think of a title that is descriptive of the work, concise and attractive to applicants.

Create the duties of the position
What are all the things that the person will be responsible for doing? Take a broad view of this and create as long a list as you need to. You will see from your extended list that many things are just variations on a theme. With a bit of reorganising, everything can be accommodated under six to eight major activities. This is what you are aiming for. There’s no point in listing every single duty. It is too messy, you may not have captured them all anyway, and leaving a bit of latitude will enable the appointee to bring some innovation to the job.

Write the main duties as active statements that express the desired outcomes of the duty. This format is also useful for selection and staff appraisal. Commencing the statement with the word ‘to’ forces an action statement and is a useful tool. Wherever possible, incorporate into the statement something that represents the level of accountability for the outcome. Use words like, ‘To be responsible for...’; ‘To ensure that...’; ‘To actively contribute to...’. Active outcome statements tend to incorporate words that are about measurable outcomes like ‘quality, satisfaction, efficient, responsive’. For example:

Passive statement – To provide support services to clients.
Active statement – To ensure satisfactory outcomes for clients through the provision of quality support services.

List the duties
The convention is to list the duties in order of priority with the most important duty first. You may want to add as the last duty something like, ‘Other duties as required’, particularly for positions that are likely to alter over time.
Decide who you want

Decide on the type of person to best fill the position

Ask yourself these questions:

● Does the person need to have any particular personal qualities, for example, a particular gender, from a particular cultural background? (Selection on the basis of personal qualities is usually prohibited by law, for instance, equal employment and anti-discrimination legislation. Check under ‘Employment’ in the government and community index of your State/Territory white pages phone book for appropriate advice.)

● What knowledge does the person need? Are there particular technical aspects of the work that require special knowledge?

● What skills does the person need?

● What level of competency is being sought? Some work provides for learning on the job. A certain level of knowledge and skills may be required to commence with.

● Are any particular formal qualifications required as a demonstration of particular competencies?

Consider any other additional features required, such as particular attitudes or values. For instance, does the person need to demonstrate a good appreciation of consumer issues related to the work?
Develop a list of selection criteria

Use the answers to the questions to develop a list of selection criteria. The selection criteria are the things against which the person will be selected. It is important, therefore, to ensure that they are what are needed to do the job, that all the major requirements are included, and that they are written in a way that enables choice between applicants. As with the duty statements, including measuring words like ‘demonstrated, high level, strong,’ is particularly useful for differentiation. For example:

‘A strong appreciation of the needs of consumers for effective participation.’

In framing your interview questions, you can then think about what sort of responses will demonstrate ‘strong’ and ‘effective’.

Provide a context

The position description, in effect, forms part of the letter of appointment. It is also the document that prospective applicants can use to be clear about the dimensions of the job. The position description needs to provide as much information about the job as necessary for both the applicants and the employee to be clear about the position. Having decided on the primary objective of the position, its title, the main duties and how selection will be made, the documentation needs to put it all in context.

An overview of the project/organisation is required, stressing in particular what the major challenges of the position are. It needs to be made clear to whom the person is accountable, the reporting relationship and positions that may be subordinate. An organisational chart is useful in describing these.

Decide how much to pay the person

This may be determined by how much money you have, be in line with the amount paid in similar situations elsewhere or be in accord with a particular industrial award.

Find the right person

Decide how to advertise the position

With the documentation complete, the task of finding a suitable applicant can commence. You need to consider where you are likely to find the person you have in mind. It is usual to advertise a position where the sort of people you want to attract will see it. For a general position, advertising in the classified advertisements section of the local or State/Territory newspaper is usually sufficient. To cast the net wider, you might consider a national paper. For very specialised positions, it may be better to advertise in specific professional or trade journals.
Create an advertisement
It is worth spending some time in preparing an advertisement to put in a newspaper. Your advertisement can easily get lost or overlooked among all the others. A boxed advertisement tends to stand out but will cost more. Charges are determined by the amount of space used and so being concise is clearly beneficial. Make sure that the advertisement provides enough information to attract the right people to enquire. Include a phone number and the name of a person who knows about the position for interested people to contact. Include a date by which people need to put in their application and ensure that this gives sufficient time for people to make their own enquiries, write an application and post it to you. Be prepared to mail the position description to prospective applicants.

The short-list

Collate the applications. Your hope will be that sufficient suitable people apply for the position for you to choose from among them. The response may be disappointing and you may consider re-advertising, perhaps through a different medium. Contact the existing applicants and tell them about the delay.

Develop a short-list. You may receive a large number of applications and will need to sift through them to determine those most suitable. Having spent the time to get the selection criteria right, your task of selection will be made easier. In the end you want to choose a smaller group with whom you can conduct more in-depth selection, usually in the form of a face-to-face interview. A number of indicators can assist in considering a short-list of applicants who will move on to the next phase of selection:
- The quality of the presentation – care and attention to detail may be important in your selection decision,
- Understanding of the position – the application may impress you as being written by someone who has bothered to find out about the position and understands it,
- Previous history – the person’s work history may suggest they have the experience, knowledge and skills that you are looking for,
- Qualifications – the person has or fails to have the qualifications considered necessary for the position.

Provide clear instructions for those applicants invited to attend an interview, including the venue and time of appointment. Leave enough time for each applicant, usually between 30 and 45 minutes.

Remember to notify and thank those people not short-listed as soon as possible.

The interview

Prepare for the interviews. The selection criteria act as a guide to the interview. You have already determined the basis upon which you wish to appoint someone. The interview process enables deeper exploration of whether the person satisfactorily meets the criteria.
A small interview panel provides for a range of perspectives for selection. Too large a group is very daunting for the applicant and difficult to manage effectively. Sometimes lots of people believe they have a ‘stake’ in the selection. Some may need to be persuaded that another panel member can serve their interests rather than increasing the panel numbers. Make sure the concerns of stakeholders have been registered and are able to be represented.

**Sort out the questions.** It’s always useful for the panel to meet before the interviews commence to arrange the venue and to get comfortable with each other. Often this time is used to sort out questions and who is to ask what. Alternatively, this can be organised when the selection criteria are being drafted or when short-listing takes place.

Formulate questions in a way that makes them either direct (if there is a specific answer) or exploratory (if you want to check out a range of alternatives considered by the applicant). Make the questions clear, unambiguous and without jargon. Write the question down as you intend to ask it so that everyone gets a similar question. Asking the same set of questions helps in deciding between people.

**Organise the process.** It isn’t necessary for every panel member to have equal question time. Dividing up the questions can sometimes result in a person asking them in an area in which they have no background. This can prove uncomfortable for all concerned. Participating in all aspects of the recruitment process can increase panel members’ confidence with a range of questions. Be prepared to nominate the areas in which you feel most comfortable. If there is little choice, explore the question area with the other panel members beforehand.

**Sort out the management.** Select a panel member who is going to ‘lead’ the discussion and generally manage the process. This person will need to remain particularly aware of how each interview is going, manage any issues that arise, give particular attention to the comfort of people and keep things on time.

**Check out the environment.** The interview process is not meant to be daunting. Being put ‘on show’ is difficult enough without physical factors getting in the way. Make sure the seating is comfortable and not arranged to disempower people (avoid sitting behind desks). Check for sufficient lighting and make sure nobody has the sun in their eyes. Provide water for panel members and interviewees.

**Receive the applicants.** Make the entry of the applicant inviting. Greet them and introduce yourself. Let them know what you represent (staff member, manager, participant or other) so that they can put you in context. Be clear about where they are going to sit (preferably near the door so that they don’t have to climb over other chairs).

Thank the person for attending and provide an overview of the process to be followed. This is partly to use up some time for the applicant to get a feel for the setting but also to enable the applicant to consider his/her own process.
Maintain good conduct. As a representative, you symbolise the constituent group. Act in a way that maintains credibility. Be attentive, affirming and relaxed. Respond to the applicant in a way that allows him/her to know that you are listening and appreciating their answers. Maintain positive body language. Start on time and avoid any distractions.

Ask the questions in the agreed order. Listen to the questions of others and the responses. Be prepared to make comment later on all of the responses. When the time comes to ask your questions, attempt to gauge whether the applicant understands your question. Be prepared to rephrase it if called upon or if the applicant appears to be on the wrong track. Feel comfortable in asking additional questions if you want to draw out a particularly interesting response or you are uncertain what the applicant is getting at. Do this following the questions of other panel members as well. Don’t overstretch the point or use up excessive time.

Conclude the interview. Make sure the applicant has a chance to ask pertinent questions of the panel or to raise anything in support of their application that has not otherwise been expressed. This may also be the only opportunity to check the names and contact details of any referees. It is preferable that this is sought as part of the person’s application. As appropriate, check out if the person has any specific needs to assist them to do the work. Be sure to acknowledge their departure by way of thanks.

Take notes. You will inevitably forget what people said and who said what. Keep note-taking as unobtrusive as possible. This may mean making notes on responses to your own questions when your turn has concluded.

Make the decision. The final decision is a collective one. Having worked through the exercise of creating a meaningful position statement, the decision process will be made easier. The challenges and duties of the job will be apparent. The selection criteria will be explicit. Somebody may stand out as exemplary in relation to the selection criteria or the decision may be a close one. Sometimes considerable debate is required to resolve a decision. It is better to keep focused on what is best for the project/organisation. It is not a decision that requires personal investment.

Check out referees. As a process of validation, satisfy yourself that the person is who he/she claims to be and that the positive values you saw have been demonstrated elsewhere. Check out any concerns you may have (these should be minor or else the decision to consider appointment has not been a good one). Be specific as nominated referees are, by and large, reluctant to provide negative comment.

Notify the applicants. Let the successful applicant know and ensure they will take the job. Advise the unsuccessful applicants. Some people prefer to do this by phone and provide some feedback to them on their performance to assist in the future.
Start the person

Organise the dates. People will be different in their timing for work commencement. Usually, people have other situations to organise, particularly in moving from one job to another.

Organise some orientation. A person starting in a new environment will be more functional if they have access to relevant basic information. Organise for a new person to be made aware of the project/organisation and the key issues, to meet the key people, to ask questions. A new environment can be challenging and sufficient time needs to be given for a person to settle in. However, a balance in orientation is required between boredom and isolation and information overload.

Gino achieves improved consumer involvement

Gino takes the view that consumers need to contribute to the shaping of positions as they arise to ensure they remain relevant to the needs of service users. He puts forward the view that consumers who will be on selection panels need to be central to this development. Consumers, Gino says, need to be involved in every aspect of the recruitment and selection process. They must not participate in a tokenistic way but be empowered to contribute to the decision by having the same information and understanding as others. Gino is particularly keen to ensure that consumers are party to the design and delivery of the orientation program and, by extension, ongoing appraisal of the staff member. The organisation responds to Gino’s views and captures them in its policy and procedures document.
Every effective group or organisation needs to have good administration practices behind it. Many groups have a lot of energy for carrying out their activities but fail because attention isn’t paid to administration. People join voluntary groups expecting to get involved in the interesting activities of the group; very few are interested in being the treasurer, answering the telephone, looking after the filing system or doing the mail. These don’t appear to be the real objectives of the group. The reality is quite the opposite. In fact these days, funding agencies require groups to demonstrate sound administration practices before money is handed over, and the administration practices are monitored before further money is granted.

One way to ensure that there is a focus on administration is to make one of the first objectives of the group the need to have a process to ensure that sound administration occurs.

**Reasons for poor administration**

1. Sometimes ineffectiveness rather than inefficiency is the problem. Efficiency is about doings things right. **Effectiveness is about doing right things right.** There is nothing more unproductive than doing unnecessary things efficiently.

2. There may be a number of reasons why people or groups don’t always carry out administration tasks well. Here are three possible reasons:

   - **Lack of skills and knowledge** – A person may spend four hours on the computer instead of half an hour because he or she doesn’t know there is an easier way of doing things (everyone is ‘too busy’ to read the manual and the group can’t afford to send anyone to a course). But not knowing costs the group in time; the person on the computer might have spent the three and a half hours doing other work. It also costs the group by creating frustration for its members, which may eventually lead them to leaving the group.

   - **Poor process management** – Groups need to have clear policies, procedures and safeguards developed and understood by all members of the group.

   - **Simple untidiness** or poor organising habits.

**Developing good processes**

A group is no different from a business in that it needs efficient and effective processes for everything from recruiting new members (or staff) to making sure that financial records are maintained in an appropriate way. All these processes need to work well together. While this may seem time-consuming and a bit ‘formal’, it’s not half as time-consuming as the results of not giving attention to good process.
Policies

Policies are the way that things get done within the group. For example, one of the group’s policies may be: ‘We will discuss the needs of any consumer who requests assistance; we may not take up the request, but we will suggest the best course for action’.

Procedures

Procedures are the specific things the group does to fulfil the policy. For example, the procedure for handling requests for advocacy may begin with a discussion between the person requesting advocacy and a member (or members) of the group. This procedure may be followed by a written request for advocacy being filled out and signed by both parties. Written requests are then filed away for safe keeping and as a record.

Controls

Controls are mechanisms the group has in place to check that what is thought to be happening with the group is happening. Controls are a way to prevent disasters. An example of a control is to ensure that the cheque account for the group requires two signatures on all cheques written.

Learn from others

It’s common to see groups and small organisations, which have very little financial and material resources, continually ignoring what others are doing, or have done in the past. ‘Reinventing the wheel’ some call it. It takes an enormous amount of time and money to begin from scratch and learn the hard way what works best. To be innovative and original, first find out if something has been done before – the chances are it has. If it has, adapt it to suit your own needs, discarding what’s not appropriate and adding bits to improve it. Contact a range of similar groups and organisations and ask about their administration practices. The chances are that, from all of these, you can come up with basic practices to modify and build on over time.

Filing systems

When it comes to paperwork, always remember two old clichés:

- Don’t put it down, put it away,
- A place for everything, and everything in its place.

There are probably many groups and small organisations that would find life easier if they had an efficient classification system for their files. A lot of people get very bored with this sort of thing, not realising how simple it is to do and how much time, effort and frustration it can save.

A good filing system has standard general headings. The headings are things like ‘Finance’, with a subheading ‘Treasurer’s report’. To create a new classification, first set some headings, then against them add in subheadings which are appropriate to the group and its activities. An example administration classification follows:
Administration classification example

**Administration** .................. originals of forms (the ‘masters’)
- insurance
- office equipment
- computer

**Advocacy** ........................ advocacy in progress
- completed advocacy
- requests for advocacy
- advocacy forms

**Auspicing** ......................... auspicing agreement
- reports to auspicing organisation
- correspondence with auspicing organisation

**Business planning** ............... business plans (may include strategic and other plans)

**Classification** .................... up-to-date copy of the classification system

**Community development** ....... current activities
- past activities
- mailing lists
- useful material

**Financial** .......................... accounts
- bank statements
- budgets
- cash flows
- cheque book
- financial reports

**Funding** ............................ original funding submissions
- new funding submissions
- reports to funding agencies
- correspondence with funding agencies
- potential funding sources

**History** ............................ live history as it happens (great for newsletters)

**Management Committee** ....... current list of committee
- minutes of meetings
- correspondence

**Manuals** ......................... advocacy manual
- community development manual
- procedures manual

**Meetings** .......................... correspondence in
- correspondence out
- group meetings
- other meetings

**Membership** ....................... current membership list
- previous membership lists
- correspondence

**Newsletter** ....................... previous newsletters
- material for newsletters
- next newsletter

**Reports** ............................ management committee’s report
- various reports
What to file

Some people say, ‘If in doubt, file it out’. It’s a good idea to file anything that is ‘official’. File everything that may be required in the future. File any useful information that may need to be used again. Get it all filed away so it’s not under some pile on a desk somewhere and everyone knows where to find it. Keep only current information on the desk and put the rest in a file or the waste bin.

Tips for good organisational administration

- Keep a diary or wall planner for noting important events, such as the group’s meetings; when reports to funding bodies and others are due; group member’s birthdays and other key events. Make sure it lists public holidays – who wants to attend a meeting on Good Friday or Labour Day?

- Phone answering can be a burden if it all falls on one person. If the group has an office, roster different people on phone duty. If group members’ home phone numbers are being listed, it’s worth considering a time limit, for example, 5.00pm to 7.00pm weeknights. Consider getting an answering machine. Develop a policy on how phone calls are to be handled. For instance, a list of phone numbers handy for crisis calls needs to be permanently located near the phone. Set limits and boundaries so that nobody is expected to take on too heavy a load.

- Keep a log book (a simple exercise book will do) for people to write down incoming and outgoing calls made on behalf of the group – just a few lines giving details of the call. This information can be used when applying for funding or making submissions. The group needs to decide on the amount of information to be recorded (for example, whether people’s names are used) to protect people’s right to anonymity and confidentiality.

- If the group doesn’t have an office, a post office box can be a suitable permanent mailing address. It’s important that all inward mail goes to one address. Nominate one or two people to collect the mail, open it and distribute it. Listing all incoming and outgoing mail is also a good idea – then nothing can go astray or be overlooked.

- Many groups use a WIP. No, that’s not a whip to get members into line. A WIP (Work In Progress) or action sheet is a useful form which shows who is doing what, with whom and by when. These need to be reviewed and updated at each group meeting. Some items may stay on the WIP for several months and this way they don’t get forgotten.

- Petty cash is used for all purchases by the group that are in cash, and generally under about $50. This requires a petty cash ledger, petty cash vouchers, a lockable petty cash tin and of course, the money. Nominate one or two people to operate the system. Whenever money is taken out, a voucher is filled in and later the receipt is stapled to the voucher. It’s important to write each transaction in the ledger and keep a running total. When the total amount remaining falls to a nominated amount (such as $100), the treasurer totals the amounts and writes a cheque (or notifies the auspicing agency that an amount of petty cash is needed) to reimburse the petty cash tin. Petty cash can cover items like tea, coffee, travel, postage, stationery and other small items.
The minutes of the group’s meetings, the agenda, the WIP and any other reports from committee members need to be forwarded to the committee at least a week before the next meeting. The minute book must be available at each meeting for acceptance of previous minutes and clarification of previous motions.

People sometimes volunteer to help with the administration of the group. They may not be involved with the group as an active member, but they may, for example, be a retired office worker wanting to help, or a student getting practical experience by helping a group. The group may be able to allocate a volunteer to take minutes at meetings, develop and maintain the filing system, or do the petty cash.

Keep a mailing list of all group members. Over time as the group expands, it is a good idea to send a flyer to members asking if they still wish to be on the mailing list.

Develop a form for new members to complete with their details such as:
- Name,
- Address,
- Telephone contact numbers,
- Issues of importance,
- Skills which they are willing to offer the group.

Transfer this information onto a membership card and keep the cards filed for future reference.
Groups and organisations are not unlike businesses in that, to be successful in the long term, they need to plan for it. The business plan is a map for the future of the group and can fulfil several functions:

● To motivate and focus the group,
● To ensure all members agree on direction,
● To enable all members to know the part they play,
● To satisfy requirements of potential funding bodies (also see 3.6: Submission writing).

There are many different ways of writing a business plan. The best way is the way that works for your group so that everyone fully understands the plan. The plan needs to look ahead at least three years and cover the following areas.

**Business plan summary**

This covers the nature and mission of the business being conducted by the group, such as:

● The kind of work or services performed by the group (for example, advocacy, mental health promotion),
● What the group intends to achieve,
● Overall assumptions and strategies of the group,
● Information on potential targets of the work performed by the group (for example, universities, mental health services),
● How the group will operate financially.

The summary is short, one page at the most. It’s as if you are telling someone in a few sentences what the nature of the group is and how it is going to achieve its goals.

**The business**

List the key elements of the group:

● What is the nature and purpose of the business of the group?
● What is its structure? (For example, independent group, auspiced group, incorporated group.)
● What is the capital? (That is, the amount of money to support the group.)
● Who has provided funding and, therefore, has an interest in the business of the group?
● What resources are needed to do the job?
Services performed by the group

List all the services the group intends to perform and the opportunities and strategies for performing these services. List the ways the group intends to improve and expand these services. The group may want to work out what help is needed for each task and nominate a person responsible for each task.

Marketing

Groups conducting advocacy and community development first need to do a little research on whether other groups exist that offer similar services and who are the targets of their services. There’s little point in trying to duplicate services that others are already adequately providing, but it’s good for groups to work together to enhance each others’ goals. (Also see 5.3: Gaining support and fundraising.) The group also has to work out how it is going to approach these target organisations. This Kit provides knowledge about some of the potential target organisations, but groups need to modify this knowledge to suit their own local area. Marketing may include strategies for getting publicity for the group and promotion. (Also see 4.9: Promotion [organisational].)

People

Within any group there are people with a whole host of strengths and skills in a variety of areas, although many may not even recognise their talents as skills useful to the group. The business plan can identify a range of useful skills and match these up with group members. The group may even consider approaching certain people who have additional skills to join the group (as long as they fit the group’s membership requirements). For example, if it is known that Bill Smith was an accountant with a small organisation for fifteen years, the group may contact him to join the group.

Learning experiences for group members also need to be considered. The gap between the skills needed and the skills present increases the risk of group failure. Skills also need to be kept up-to-date.

Sometimes it’s appropriate to bring in outsiders to assist the group, such as external facilitators and those with specialist knowledge (for example, lawyers working in legal advocacy). The plan can cover the situations where this may be warranted, how such people can provide assistance (for instance, attending group meetings), with suggestions for people who can provide these services.

Finances

One and one has to equal two, and the group needs to make sure that the money from funding sources covers all the expenses. It is not acceptable for individual members to have to dig into their own pockets to cover telephone or other costs. The business plan first lists all the money that the group knows it will definitely have and a second corresponding list of expenses that does not exceed the first list. The group can also list money which it anticipates it might have and what this money might be used for if it actually does arrive. The group might explore ways of carrying out work as inexpensively as possible to achieve the most with its limited money.
Finally

When the plan is being written, thought needs to go into considering who the plan is targeted to (group members, funding agencies), what they need to know and what message is being put across. Some final tips which may be useful in preparing a business plan include:

- Keep it simple,
- Keep it clear – get someone who doesn’t know much about the group’s activities to test-read the plan and comment on its clarity,
- Don’t include opinions – it has to be fact,
- Be positive but not over-optimistic,
- Order the information in the plan under relevant headings,
- Use diagrams, drawings, tables – whatever members feel are useful,
- Use lists of points (like these dot points),
- Remember what the reader of the plan needs to know.
The group may have dedicated and hard-working members, a sound organisational structure, and some excellent ideas on the issues concerning the group, but if no one gets to hear about it, there is a problem. Promotion is telling others about the group and the work it performs. Promotion is necessary for the group to develop and grow.

Promotion can be carried out through a variety of ways, such as:

- Establishing a newsletter,
- Having a website on the Internet,
- Getting published,
- Producing and distributing brochures and flyers about the group,
- Producing posters,
- Distributing business cards,
- Submitting articles to newspapers,
- Going on talkback radio or television,
- Holding public forums,
- Hosting social events,
- Speaking at meetings of other groups, organisations, places,
- Speaking at conferences,
- Being in everyday communication with others.

The above list is only limited by the imagination of group members. But, whatever the mix of methods of promotion are chosen, the group needs to make sure that there is some consistency. The group may be targeting different groups, organisations or sections of the community and may have unique messages for each, but the various messages must not conflict with one another.

All group members need to be aware of these messages and communicate in a way that is consistent with the message on the poster, in the talk given at the university, in the newsletter and other places. If someone asks a group member about a particular workshop that the group is offering, and the member doesn’t know anything about it or gives wrong information, it can be a lost opportunity to undertake the work that the group is established to do. A strategy to ensure that awareness and communication is consistent with promotion is for all group members to be involved in a planning process.
Planning promotion

In developing a strategy for promotion:
- Consider the target audience,
- Consider the messages you want to get across,
- Choose communication methods to do it,
- Decide what will be done and by when,
- Decide who is going to do it,
- List overall goals for communication,
- List any general messages you want to get across about the group and its activities,
- List the various target audiences,
- Develop sets of messages to target audiences,
- List the key messages you want to get across to target audiences.

Once the strategy is written, each statement needs to be reviewed. For example, do they reflect the viewpoint of the receiver or of the group? Frame the messages so they contain benefits for, or at least reflect the interests of, the people receiving the message. Importantly, is what’s being said true? Over-promising and under-delivering can only result in loss of credibility.

As with most group activities, developing a promotion plan is a process that matures, like fine wine. The third or fourth plan will probably be a masterpiece compared with the first.

Evaluating promotion

The group needs to know if its promotion activities are working, which ones are the most effective and which ones are a waste of time and money. One way to find out is to distribute a questionnaire to people on the mailing list to find out which promotion activities they are aware of. Another way is to ask people when they make enquiries about the group where they got their information from. (Also see 2.10: Reflection and evaluation.)

Some ideas for promotional activities

- If there is a flyer for an event, make sure all group members have copies to distribute to people they talk to. Many people will not follow up on something they hear about, but will if they have all the information in writing.
- When brochures/posters concerning the group are distributed for permanent display, keep a list of where they went. If any details change, like the venue or meeting time, it’s easy to know where to send replacements or stickers with the new information.
- University or college art departments can be approached to design posters and brochures. Some classes may even use it as part of the students’ assessment. The group then gets a professional design for no cost, and the student who designs the successful artwork gets something worthwhile for his or her portfolio, as well as doing something to help the community.
Don’t forget to use the local, free newspapers. Most have ‘what’s on’ sections that publicise events or regular meetings for no charge.

If there is a high profile guest speaker at a meeting, publicise it to attract new members and to raise the profile of the group.

When group members attend seminars related to mental health, be sure they take a good supply of the group’s brochures to distribute or leave at the registration desk and other appropriate places.

Design a letterhead and ‘with compliments’ slip for the group. Stick to ‘one look’ for the group’s stationery.

Play a large role in Mental Health Week.

The Internet

Many opportunities now exist to obtain world-wide promotion inexpensively through the Internet. Readers interested in using this approach to marketing are advised to also see 2.4: Finding relevant information.

Tips for good promotion

- Don’t forget to state the obvious, such as the guiding principles of the group,
- Plan for good communication – keep in mind the activities of the group and the information it wants to communicate,
- Be consistent with the information, while angling the message to the needs of specific groups,
- Conduct formal promotion, such as through brochures, and informal promotion, such as in everyday conversation,
- Take opportunities to get the message across.
Becoming an incorporated body

A group may decide that it should become incorporated as a public body. It is not a requirement of organisations to do so, and most consumer and carer organisations will not find the need.

Those that may want to do this as part of the self advocacy process are likely to be:

- Carers and/or consumer groups wishing to establish a public company through which to operate a consulting or other business,
- Organisations wishing to attract grants but not wanting to be auspiced by another group.

The major options are to form:

- A public company, limited by shares or guarantee,
- A company established by Act of Parliament or Royal Charter,
- An incorporated association under the relevant State or Territory association incorporation legislation.

Incorporation as a company places people under the legal duties and obligations of the Commonwealth Corporations Law. As an incorporated association, the organisation is bound by the Associations Incorporation Act of the particular State or Territory.

Incorporation creates a ‘legal entity’, meaning that the incorporated body takes on a life of its own. It is considered legally separate from its members. An incorporated body can sue or be sued, own assets and enter into contracts in its own right. While the incorporated body is legally liable for its debts, this liability is usually limited to its assets or to the contribution of its members. Such limitations extend to members of the committee of management and financial members. However, committee members can carry a personal risk where personal negligence can be proved.

For people undertaking private consulting work, it is not always necessary to form a company. Some clients, however, will only enter into contracts with companies.

Incorporation may be desirable for organisations seeking grants for particular projects, ongoing funding for service provision or even to maintain a social club that involves the handling of member fees or other reasonably large sums of money.

An alternative to incorporation is to approach an existing incorporated association to auspice the project and manage the grant within its existing structure. (Also see: Engaging networks and organisations in the Knowledge and Attitudes Booklet.)

The concept of incorporated associations as opposed to company structures was developed essentially to create a legal means for organisations that were not intent on engaging in commercial or profit-making activity. Not-for-profit companies will usually be incorporated under an Associations Incorporation Act. Not-for-profit means that any surplus funds of the organisation may be used for improvement or extension of the
organisation’s assets or operations, but cannot be allocated to the personal use of shareholders or members.

In forming a company it may be best to seek the advice of a solicitor or accountant. Forming an incorporated association is fairly straightforward and requires lodging the appropriate documentation with the particular State/Territory lodgement authority and paying a small fee.

The ‘constitution’ will form part of the documentation. The constitution will usually describe the ‘Statement of Purposes’ (the intent or aims of the incorporated body), and the ‘Rules of the Association’. A model constitution is usually provided by the respective State/Territory lodgement authority to make it consistent and simple.

The rules of the incorporated association will refer to such things as membership and fees, voting rights, committee membership and conduct, financial accountability and dissolution.

An incorporated association is required to maintain accurate financial records and to provide an annual financial statement. Many funding bodies require financial statements to also be independently audited. Annual returns must be lodged with the respective State/Territory lodgement authority. These usually include an annual report, an audited financial statement, certification of an annual general meeting, a statement of any resolutions passed at the annual general meeting and any prescribed fees.

A management committee is required for an incorporated association. Such a committee has certain legal duties including:

- Fiduciary duties – to act in the best interests of the organisation and to act in good faith,
- Duties of skill and care – to act with reasonable skill and care,
- Incorporation regulatory requirements – to act according to the requirements set out in the governing legislation and the constitution,
- General regulatory requirements – to act in accordance with all other relevant laws.

Note: Nothing written herein constitutes a legal opinion. Other forms of advice, including legal advice, should be sought prior to pursuing incorporation.

References
Advocacy can involve specific tactics targeted towards achieving an identified goal. This section of the Kit focuses on skills and strategies which link individuals, groups and communities to increase the power of their advocacy activities.

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5.1 Strategic thinking in targeting the message

Once you have a good understanding of the advocacy activities you wish to undertake, strategies need to be developed to target these activities to appropriate people and/or organisations. It’s one thing to know generally what needs to change; it’s a different thing to adapt this knowledge to most effectively bring about change in a variety of situations and settings.

Who are the stakeholders?

For every issue that you work on, the stakeholders need to be identified. Stakeholders are all those individuals and organisations that are included in, or affected by, a specific issue or event. The stakeholders differ from situation to situation. Sometimes the stakeholders are the same for different situations and, while they may have supported the group on a previous issue, they may oppose the group on a different issue.

There will be times when you will need to work with the people you want to influence, and there will be times when you work in opposition to them. There will also be individuals and groups who are not involved directly in your advocacy efforts, but who will be affected by them either positively or negatively. For example, if you are advocating for television stations to develop a ‘code of practice’ for reporting crimes alleged to be committed by people living with a mental illness, this will have an effect on all media outlets. In this situation all media outlets become stakeholders in this issue.

The group may never even come into contact with the whole range of stakeholders. For example, all community members are stakeholders in attempts to change community attitudes towards mental illness and to people living with mental illness. However, advocacy groups working on this issue are hardly going to come into contact with all members of the community.

The group may consider developing a list of the stakeholders. The list might start with a broad grouping of those who may be affected by the changes proposed, for example, ‘the medical profession’. Follow this with a specific list of individual people from various organisations within these broad groupings, such as, Dr John Smith, Smith Medical Centre. It needs to be indicated on the list whether the stakeholder may be in support of your advocacy or in opposition to it.
**Who are the targets?**

Targets of advocacy are those people who are in a position to change the things that you or your group believe need changing. (Also see: 5.6: Lobbying.) As discussed there, it is important to be sure that you have accurately identified the appropriate people as targets for advocacy. Targets may include those in positions of power and influence within a range of organisations such as:

- Mental health services,
- Universities providing courses to students of the mental health professions,
- Education providers in general,
- Media outlets,
- Police service,
- General community,
- Agencies involved in providing services (such as social security; housing),
- Community partners/organisations,
- Government officials.

This list is only limited by the resources of the individuals and groups involved. Within each of these targets are people who can facilitate change; they are not just organisations or ‘parts of the community’. Within them all are people of power who have a say in how things run. People often talk about the ‘culture’ of organisations as if organisations were living things that made all the decisions: ‘It’s not our fault consumers and carers aren’t on the management committee; it’s the culture of the place’.

Behind the culture are individuals who have the power to bring about change if their hearts are in it. The task for the group is to identify these people. This information may be obtained from other advocacy groups or organisations who may have a list of such people. Another way is to contact the organisation and obtain the contact details of the most senior person.

**Developing strategies**

Recognising that there are individuals who can help bring about change is the first step. The next step is to develop strategies to have an effect on these individuals. It’s quite likely that they don’t operate alone, but may chair a committee or board where votes are taken on various issues. In this case, advocacy activities need to involve all members of the committee or board.

The sorts of strategies that you may come up with depends on the interest these people have in the issues which your advocacy is concerned with. Strategies need to be tailor-made to suit each situation. The group needs to consider what these issues and its proposals mean to the people who are in a position to facilitate change, and what the repercussions for them may be. For example, while the general manager of a television station may agree that he/she could (should) direct the news reporters and presenters to never make any sensational stereotyping links between horrific crimes and mental illness, he/she may fear repercussions from the station owner, including being sacked.
If the people, like the general manager in the example above, have a lot to lose from the sorts of changes you are advocating, then the strategies and tactics need to be more confrontational than for those who stand to benefit from the proposed changes. However, the decision whether, and when, to be confrontational must be made cautiously, and after other avenues have been exhausted.

You may find that targets of advocacy benefit from your proposed changes. When conducting advocacy and developing alternatives, groups should always attempt to present their alternatives in ways that are most likely to provide benefits to the target organisation or the community as a whole. The group is much more likely to get support this way.

Generally, the people you are trying to influence will have some interests that agree with your advocacy issues and some interests that do not agree. When this occurs, use a combination of strategies to strengthen the compatible interests and weaken those which are incompatible.

In the early stages of advocacy with a particular organisation, it’s important to structure arguments so that individuals in positions of influence are not pushed into a corner. (Also see 1.6: Interpersonal communication and 1.7: How to influence people.) If they are, they are likely to come out fighting, determined not to give an inch. It may turn out, after every other strategy has failed, that this approach is called for, but it needs to be kept as the final effort.

Also see:
1.10: Family involvement in service delivery to consumers
2.5: Managing change
2.6: Gaining support from service providers
5.2: Creating networks
5.6: Lobbying
5.7: Developing a campaign

References
5.2 Creating networks

Personal networks

In all walks of life people create personal networks. Usually, they are formed through the contacts made through new experiences. They may be relatives, close friends or casual acquaintances. That everyone has some form of network indicates how fundamentally important they are. People tend to value the support, comfort, company and exchanges that others provide. Creating personal networks in advocacy is merely an extension of what people do naturally but with additional purpose.

It may be that your existing personal network is the one you choose for acknowledgement of, and contribution to, your advocacy. For some people, the usual network of relatives and friends is insufficient to support advocacy activity. They may be supportive but unable to understand the issues, perhaps because they have not had the same experience as you, or you require a different type of knowledge or support.

You may want to create additional networks of people that can meet your needs. How this happens is a matter of personal preference. Some people develop networks around them as they move through their experiences within the mental health system. Significant networks have developed among consumers through chance meetings while in hospital or attending community-based services. Other people look around for groups with similar ideas or ambitions. Engaging with an existing consumer or carer group is a good place to start.
While personal networks for some people may be the same as their friendship group, for others they may be quite separate. It may be that a group of friends meets a particular set of needs but has little interest in your advocacy activities. You may engage with different people for different purposes.

Personal networks require some effort to be sustainable, particularly where the people are not your usual set of friends. Periodic, infrequent meetings may mean that the thread of mutual thought and activity becomes lost. People tend to be members of a number of networks and move and grow with them. Periods of inactivity between people may mean that when people meet again they find they have ‘moved on’ in their thinking and actions and that the common understanding they had is no longer there.

Sustainable networks usually develop out of mutual need. This means giving as much as receiving. Personal networks will only survive through a beneficial exchange between people.

The major elements of personal network development in advocacy are:

- **Recognise the value of not doing it alone.** While considerable change has come about through individual effort, burden can be eased through collective action. Engage people in your network who are genuinely supportive of your advocacy activity. Blurring the roles with your friends may cause some of them to drift away.

- **Become clear about your own needs.** Are you looking for emotional or physical support, increased knowledge, to share ideas, to become active with a group, to achieve a sense of belonging? Clarity around your own needs will assist in identifying appropriate networks.

- **Consider joining an existing group of people who are active in advocacy.** These are prearranged networks within which you can find a place. They will usually be aware of the kinds of issues you bring with you, have a wealth of knowledge and experience, access to information and well-developed support systems. They will save on the energy required to put together your own advocacy network and provide a platform for exploring new ideas and ventures.

- **Use your networks.** Developing networks in advocacy does have a purpose. Whatever your purpose is, be it information, support, action or whatever, it is there to be used. Establish new contacts through existing contacts. Understand what each person has to offer. Let people know about your interests and what you can offer them.

- **Don’t abuse your networks.** Personal networks are a loose affiliation of people. Each person comes to it for their own purposes, with varying levels of formality and the freedom to participate or withdraw. The participation of each individual needs to be respected. Consider the importance of remaining sensitive to individuals within the network; don’t expect more than people can give; give as much as you receive.
● **Sustain your networks.** As loose affiliations of people, personal networks will drift between issues and events and the motivation and interests of individuals. Personal networks are sustainable through organised contact.

Some of the things you can do are:

- Keep a list of contacts (see 2.9: Managing a contact list),
- Develop a schedule for keeping in touch with your contacts,
- Keep notes of useful information that you can share with other people,
- Organise meetings and discussion topics,
- Contribute to meetings that others have organised,
- Be an active organisation member,
- Contribute to organisation newsletters,
- Follow through on those actions to which you have agreed.

**Organisational networks**

Change is influenced from many quarters. Consumers and carers bring their own perspective to the requirements for change, as do service providers, administrators and a range of concerned individuals. On occasion the objectives of all the players appear to be the same. Clearly, opportunities exist for collective action between peer groups and between a range of mutual interests.

The higher ideal of advocacy – social justice – is an issue in the minds of many groups of people. Many disenfranchised groups are active in trying to bring about a more just and equitable society. Groups and organisations active in mental health advocacy may identify opportunities to link with groups for mutual action outside of the mental health sector.

Networking between organisations and groups has the same purposes as personal networking. It provides opportunities for sharing ideas, strategies and support in both informal and formal settings. It provides for collective political strength.

Networking between organisations is, itself, a political event that needs to be considered carefully. Organisations may link very informally around mutual exchange and collective purpose. They are able to retain individuality and autonomy. As links become more formal, issues of control begin to arise. Who is to be seen as taking the lead on a particular event? Who will manage the effort? Where will meetings be held? Such questions may symbolise moves to establish a position of control that can lead to conflict. Being open about these issues will assist.

Formal networking between groups may take the form of establishing an umbrella or ‘peak’ organisation. This new organisation is seen as the ‘spokesvoice’ for the organisations that comprise its membership. Peak groups tend to be supported by government sponsorship as it is easier for a central administration to interact with one body rather than many. The risk to the member groups is that the peak organisation becomes caught in representing the range of agendas of the member organisations. It becomes in danger of expressing only a ‘middle-of-the-road’ viewpoint because it has too diverse a range of interests to protect. It tends to moderate rather than initiate progressive, politically relevant action.
A range of links and networks is relevant at different times. Issues and opportunities come and go. Linkages tend to form around issues. Consequently, flexibility and adaptability are vital for effective networking. Inevitably, organisations require a lot of energy to develop and maintain the range of linkages that are useful.

It may be important for consumer and carer interests to develop links with government and service providers for mutual advocacy activity. These networks offer substantial opportunity for effective action provided the agenda is truly shared. At the same time they are open to producing conflicts of interest. Such linkages may best be considered tentative and temporary.

Given the effort required to sustain organisational networks, you may want to consider your purposes in forming linkages. They may be about:

- Bringing resources together,
- Producing or exchanging information,
- Providing mutual support,
- Engaging in broad campaigns,
- Exploring ideas and options and clarifying issues,
- Coordinating effort and strategic planning,
- Providing education and skill development,
- Challenging ideas, attitudes and strategies and allowing for self-reflection and evaluation.

In assessing the relative value of pursuing more formal links, you might want to consider:

- Why do you want to speak to them?
- Why would they be interested?
- What do they currently think of you?
- Why do you think this?
- What can they offer you?
- What are the benefits and drawbacks of joint engagement?
- What do they gain?
- What do you gain?

References

National Depressive and Manic Depressive Association (DMDA) Leadership Handbook, Chicago
Victorian Advocacy Workshop (1994) Towards More Effective Advocacy for People with Disabilities in Victoria, YWCA, Melbourne
5.3 Gaining support and fundraising

One of the first barriers for new groups to jump concerns the ‘root of all evil’ – money. Any group needs money to operate and develop effectively. Some groups can get by with very little, while large groups rely on annual grants of $50,000 or more. Grants of money are empowering for groups, as it is the group that decides how the money is specifically spent. Financial support can also be obtained through a range of fundraising activities.

Groups might consider obtaining material support such as office space, a place for meetings and donations of computers, videos, office furniture, fax machines. Some groups are provided with vehicles by corporate sponsors and community service clubs. Material support can be very useful for the new group when all you have is a bunch of people with some good ideas.

Support can also be given by people offering their time to the group, such as external facilitators and guest speakers. Knowledge is power, and if people are willing to share their knowledge then it’s too good an offer to refuse. The group can access such people by writing or telephoning them and asking for their assistance. It can be surprising how many people are willing to help.

Fundraising

Section 3.6 on Submission writing covers how to actually prepare a submission for funding, so in this section possible funding sources and some suggestions on how to make the group and its work attractive to potential funders and supporters are covered.

Potential funding sources

Commonwealth, State and local government departments. Information about funding can be obtained by telephoning the government departments that are related to the needs of the group. Some examples are:

**Commonwealth government**
- Department of Health and Family Services
- Department of Aboriginal and Torres Strait Islander Affairs
- Department of Employment, Education, Training and Youth Affairs
- Human Rights and Equal Opportunity Commission
- Department of Veterans Affairs

**State government**
- Department of Health
- Department of Family Services
- Department of Housing
- Department of Education
- Department of Community Services
- Department of Training
**Local government** (councils)
- Community Services
- Health

These are just some examples and there are sure to be many other sources of government funding in the State/Territory and local area. Each State/Territory in Australia has a Council of Social Services which has information on funding sources within the State. There is also an Australian Council of Social Services (ACOSS) which has similar information on Commonwealth sources.

Some examples of grant programs from various government departments include:
- Advocacy – Disability Services Program,
- National Mental Health Strategy Projects,
- Commonwealth Mental Health Branch Funding Program,
- Mental Health Community Organisations Funding Program (State Mental Health branches/units),
- Education and Training Programs,
- Community Housing Programs,
- Health Promotion Grants,
- Young People’s Health,
- Community Development Assistance Grants (local councils).

**Philanthropic Trusts.** A philanthropic trust is set up by people or organisations to provide funding to those who fulfil the strict guidelines laid down by the trust. A number of organisations are now obliged by government licensing bodies to return a percentage of their profits to the community. Major examples of these include casinos and cigarette companies, but many large national and multinational companies also have such trusts. Some examples are:
- Casino Community Benefit Funds,
- Gaming Machine Community Benefit Funds,
- BHP Community Trust Grants.

Detailed information can be obtained from the Directory of Philanthropic Trusts which lists hundreds of grants available. Groups need to meet certain requirements to be eligible for such grants. For example, groups need to be registered with the Australian Taxation Office as a charity or be auspiced by an organisation that has such registration. (Also see: Engaging networks and organisations in the Knowledge and Attitudes Booklet.)

**Corporate funding and/or support.** As government funding is becoming harder to obtain, many groups and organisations look more and more at business organisations for support. Large multinational companies like McDonalds often support community groups and activities. Many small groups obtain substantial support from large businesses, as well as from small local businesses. Sometimes all it takes is being confident enough to approach these businesses through their public relations manager or other appropriate person (also see 5.6: Lobbying). Local photocopying and printing businesses can be approached for ‘freebies’ or good deals. Ask around the members of the group to see what connections they have.
Service Clubs. Many groups have received invaluable support from service clubs such as Rotary, Apex, Lions. Most of these clubs are set up for the specific purpose of raising money to donate to worthy community groups. If the group sends a speaker to address a particular service club, this may motivate the club to raise money for the group.

Attracting potential funding and support sources

The Queensland Council of Social Services (QCOSS) has published a very good guide to obtaining funding called Funding Resource Manual. Each State has a Council of Social Services and readers are recommended to contact their State Council. QCOSS suggest four rules for the group to follow to increase opportunities to obtain funding:

1. Establish your image. Know what the group is about and communicate this. Both you and the funding bodies have to be confident about your stability and purpose as a community group.

2. Thrash out your idea for funding thoroughly. The group needs to plan the process of obtaining funding and decide on a clear plan of action.

3. Get comments and support. Contact other groups and organisations that have previously been down the funding track: they will have invaluable advice (and stories of woe). Develop a prioritised list of likely and appropriate funding sources and approach a representative of each source. Discuss your ideas with them and note their advice.

4. Match the ideas of the group to the funding available. If the group has very strict and rigid ideas about the work for which they request funding, then opportunities are correspondingly restricted. The group can change their ideas, but funding sources do not change their guidelines for funding. Often it comes down to words and the meaning placed on words. For example, a funding agency may refuse to give funding for ‘advocacy’, but may give grants for ‘community development’. When this occurs, modify your terminology to match that of the funding agency. It’s what you intend to do with the money that’s important, not the words that people may choose to describe the work.

For skills in actually completing a funding submission, also see 3.6: Submission writing.

References

Queensland Council of Social Services Funding Resource Manual, QCOSS, phone 07 3832 1266, fax 07 3832 4119

Directory of Philanthropic Trusts, available from State/Territory Councils of Social Services and held by most libraries.
Newsletters are an essential way for groups and user-run organisations to broadly communicate the activities they are engaged in. However, they can be far more than just a method of giving information. Newsletters are vitally important in sustaining the interest of present members of the group and its supporters, as well as a means of attracting new members and supporters. To many people, newsletters can be one of the most important services provided by the group.

Newsletters vary a great deal, depending on the resources available – both monetary and the number of people available to assist with preparation, editing and distribution. Before production can begin, a number of decisions need to be made based on the resources available. Some organisations have quite elaborate, glossy newsletters; others are simply several pages stapled together at the top left corner. What is important is the content and the distribution.

Some of the decisions that need to be made about starting a newsletter include:
- Amount of funding available,
- Number of people and amount of time available (must be genuine commitment),
- Title of the newsletter,
- Overall appearance of the newsletter,
- Content and layout of the newsletter,
- Distribution and frequency.

**Amount of funding available**

There isn’t much point attempting to produce a newsletter until the group is certain it can adequately cover the costs associated with printing, photocopying and mailing. Generally, personal computers with standard word processing programs can be used for most jobs, although some groups do use dedicated desktop publishing software. If resources are scarce, it’s best to start off ‘humble’. Photocopying is a big expense, generally costing anywhere between 5 cents and 20 cents for each A4 page (the standard paper size). Postage is the next biggest expense. After the initial decisions are made, the group needs to estimate the actual cost of production, photocopying and distribution. Decisions about the size and type of newsletter may then need to be revised, depending on the amount of funding available.
Number of people available

Like many aspects of voluntary user-run groups, the production of a newsletter requires dedicated, hard-working people. The group might aim to find people from outside the group to contribute articles to the newsletter, as well as to locate articles that are appropriate to reproduce. However, the reality is that it is often difficult to obtain outside contributions, so there must be people within the group willing and capable of writing articles themselves.

Once the group has identified members who are prepared to commit themselves to working on the newsletter, an editor needs to be chosen. The editor decides what material goes in the newsletter and generally oversees production. It may be that the editor does most of the typing of articles in the beginning, with training then provided to others to take on this task. The editor takes responsibility for ensuring that deadlines are met and that the content reflects the guiding principles of the group and the wishes of the group members.

The biggest single task involves the collation of pages, stapling, folding and taping closed the completed newsletters (as well as applying postage stamps if they are not ‘postage paid’). It is important to have as many members as possible involved in this to get the job done quickly. Have some group fun after the newsletters are mailed; members are more likely to turn up again next time and repeat these menial tasks.

Newsletter tasks and deadlines need to be realistic and clear to avoid any misunderstandings about duties and tasks of the people involved. Careful attention to planning and organisation can make a newsletter an enjoyable and satisfying experience for all involved.

Title of the newsletter

The title of the newsletter needs to be decided by all members of the group to reflect the identity and purpose of the group. It may be clever, catchy, creative and informal, or it may be descriptive and formal. Whatever the group comes up with, the title needs to suggest to the reader the general tone of the newsletter and the nature of the activities of the group.

Many groups and organisations use a distinguishing sign or logo, as well as the title, on the front page of their newsletter. For example ARAFMI Brisbane Inc has the coolibah tree as a logo. A logo can also be used for the group’s letterhead and other stationery.
Overall appearance of the newsletter

While acknowledging that the content of the newsletter is the most important factor, it’s not much use if not many people can read the print. Consideration needs to be given to the requirements of readers. Some fonts look very clever and arty but can be very taxing on the eye and brain. It’s best to choose clear, easy-to-read fonts in a size that doesn’t require detailed inspection. It’s false economy to try to save money by putting a lot of information into a newsletter through the use of a small font.

Thought needs to also be given to the ‘look’ of the newsletter. While the format does not need to be a ‘sophisticated’ design on glossy, heavy paper, it does need to display the information in a way that makes it easy and enjoyable to read. Some newsletters use just one column, others use two or three columns (all can be managed in a basic word processing program). Once the newsletter has been in production for some time, it’s always a good idea to survey the readers to find out what kind of style they prefer: maybe try several layouts first and then take a survey.

Unless the group has a lot of money, cost will be the factor determining the overall look of the newsletter. For groups producing a newsletter for the first time it’s best to keep it as simple as possible in the beginning. Readers will understand that, as a non-profit community group with little money and few members, it’s not possible to produce fabulously glossy works of art. Again it needs to be stressed that it is the content, readability and distribution that counts the most.

Content and layout of the newsletter

Content will vary with each issue, but there needs to be some continuity from issue to issue. The newsletter is likely to have a few regular features, such as an editorial, letters to the editor, calendar of events, work in progress, future activities. These features can then serve as the framework for each issue. If the group networks with other consumer and carer groups their information on current and planned activities can be included. (Also see: Engaging networks and organisations in the Knowledge and Attitudes Booklet.)

The layout may vary with each issue, but it is important to use some consistency to make it easier for the readers to find the information they’re looking for. For example, regular features can appear on the same page each issue, if this is possible. The number of pages can remain about the same each issue as readers usually find comfort in consistency of style and format. However, as the group becomes more established and resources increase, a slowly-increasing number of pages in the newsletter is not a bad thing (to a limit, of course).

Remember, all of the layout tips listed below can be carried out on a personal computer using a current word processing program.
Tips for an attractive layout

- Use a larger font for the headings, different from the rest of the text,
- Use decorative borders and lines,
- Make use of ‘white space’,
- Use graphic symbols to illustrate articles,
- Use a combination of fonts for different articles,
- Use subtitles to divide up text,
- Use a scanner to insert photos if possible (readers like to see photos of people they know),
- Number the pages.

Frequency of publication

Decisions about the frequency of newsletter issues depend on the level of funding, resources and the needs of the group and the readers. Members must decide how often the newsletter can be produced to accomplish the group’s communication goals. Generally, non-profit community groups produce newsletter issues either monthly, two-monthly or quarterly. It is quite difficult to maintain any form of regular readership if a newsletter is produced less than four times a year.

Targeting the newsletter to an audience

Newsletters need to target a variety of audiences. As the group goes through various stages of development, the primary audiences may well change. For example, when the group is newly formed, the primary target audience is probably potential members. However, keep in mind the needs of all target audiences when preparing the newsletter. These may include:

- Group members,
- Potential members,
- Members of other consumer and carer groups,
- Potential financial sponsors,
- Allied community organisations,
- Service providers,
- Targets of advocacy,
- Politicians and bureaucrats.

The trick is to write and edit the newsletter in such a way that anyone reading it can not only understand it but can be supportive of the group and its work. A purpose of a newsletter is to obtain supporters, not alienate people and groups. Avoid strong opinions putting forward rigid lines of thought, such as pro-medical model, anti-medical model, pro-medication, anti-medication. Avoid jargon (of any kind) and abbreviations.
Remember that newsletters are not just a way for members to air their gripes. Newsletters should never contain material which is meant for members’ eyes only, as newsletters can end up anywhere. Editors must be very careful that potentially libelous or defamatory material (that is, material which makes negative accusations against another person or organisation that can’t be proven) is not printed.

**Distributing the newsletter**

So far the content and readability of the newsletter have been covered. The third important aspect is the distribution. The first step in distribution is establishing a mailing list of group members and the various audiences that the group wishes to target (as discussed earlier). A new group may borrow a mailing list from another group that is carrying out similar activity, or use a resource directory (such as the Lifeline directory) to compile its own. The yellow pages phone book is also a good source of individuals, professionals, organisations, potential financial supporters and media contacts that the group may wish to include on the mailing list. All of these need to be contacted by phone to verify the addresses to ensure that newsletters reach their destination.

Mailing lists have to be continually updated as addresses change; new names have to be added and some names need to be deleted. This needs to be done at least every two or three months. **Enquire at the post office to check whether the group qualifies for bulk mailing rates or other discounts.**

It’s a good idea to produce extra copies of the newsletter for hand delivery to places where target audiences can pick up a copy, such as:
- Other community organisations,
- Community health centres,
- Hospitals,
- Workplaces of the target organisations (the media, police, universities, schools, social security offices and others),
- Doctors’ offices,
- Churches,
- Government offices.

Permission must always be sought before leaving newsletters at the above locations as the group may receive complaints from the organisations or the newsletters may simply be thrown out with the rubbish. Newsletters can also be sent out to people or organisations whom the group is lobbying as a way of informing them of the group’s activities. Information packs detailing activities of the group can also contain current newsletters.

The skills listed here are designed to assist consumer and carer groups in developing an appropriate and effective newsletter. Besides using this material, it is also recommended that groups contact other groups and organisations which currently produce newsletters to obtain further tips.
A major target of consumer and carer advocacy may well be media outlets such as newspapers, television and radio stations. However, the media can also be used as a tool to undertake advocacy and provide information to the general community. Many people in today’s society obtain their health and mental health information through the media directly and not from health professionals. Being able to effectively work with the media is essential in undertaking advocacy and community development.

Working with the media at first can seem to be an intimidating experience. It’s important to get to know the people in the local media to establish a positive relationship with them and reduce feelings of intimidation. The local media can be viewed as a valuable educational resource for the group.

One way to establish a positive relationship is to meet with various media representatives and supply them with information on mental health, what your group is doing, and generally try to convince them that the group is an authority for them to contact in the future. In this way the media can make contact with the group as well as the group going to them. It’s all about reciprocal arrangements: give them what they want (topical stories to interest their audience) and they give you what you want (community awareness).

**Developing a media plan**

By developing a media plan, your group can be prepared to swing into action when the situation arises. Firstly, the group must consider what messages it wants to send to the community as well as to target groups or organisations. By repeating these messages through various avenues, the group’s presence can be established in the community and the audience constantly reminded what the group is about. The messages need to be presented in ways that not only sell them to the reporters and editors, but have an influence on the audience.

You may want to think about whether the message is for the whole community or part of it. If it is for a particular audience, you may decide that a particular medium is more suitable than others, such as local papers for local issues, women’s magazine’s for issues relating to women, the Sunday paper for a feature article, television for on-the-spot news.

The plan also needs to provide guidelines on the **rights of privacy and confidentiality** of those who wish to remain anonymous. With appropriate guidelines in place and followed, people can remain anonymous and present their thoughts with passion and insight.
Contacting the media

Compile a list of media organisations, detailing the names of individuals and their organisations. Update this list regularly to ensure a complete and current list of reporters and media outlets to call on when the opportunity or necessity for media exposure arises. You may find that some media outlets have specific people assigned to cover particular areas, such as health, social justice, community. You may also find that some of these people are empathic to your causes. Cultivate these relationships as they can be extremely valuable at times when you most need assistance. One way of compiling a media list is to ring the various newspapers (including the local community papers), television and radio stations and request the names and phone numbers of the reporters likely to cover the issues which affect your group.

Making contact with the media can be achieved in several ways. You can fax information to the media. Some people report that faxing is preferred to mailing as faxes arrive quickly to meet deadlines, and they seem to indicate a sense of urgency through their immediacy. You can mail information packages about your group and its activities to reporters of the various media outlets. Information packages can include newsletters (also see 5.4: Developing a newsletter), information sheets and a list of activities that your group has previously been involved in (especially media activities) or wants to become involved in. The package can be accompanied by a covering letter from a group representative and include details on how appropriate representatives of the group can be contacted.

Another way of making contact with the media is to simply ring them up, state your business and offer to meet with them to discuss the activities of your group. If they are too busy to meet with you, offer to mail them an information package following the conversation. Remember to thank them for their time.

You may want to keep a record of what reporters have presented on areas of interest to you, including the quality of these reports. This can be done by keeping a scrapbook of newspaper clippings, either as an individual or on behalf of the group. Some community mental health organisations subscribe to agencies which send copies of media articles on subjects nominated by the paying organisation, such as articles on ‘mental health’. It may be worthwhile to contact such community organisations to find out if they do subscribe, and if they are willing for you to browse through the material and make copies of articles of interest.
Establishing the group’s credibility

To establish the group as a resource that the media can use, the group must first establish its credibility. The following guidelines can assist in this:

- Always provide honest information—the group’s credibility can shatter if a reporter finds that he or she has been misled (reporters from various media outlets refer people to each other, so one bad experience can lead to a negative response from all media).
- Never speak as ‘an individual’ if you are representing the group (for example, do not say, ‘this is the group’s position, however, personally I believe...’).
- Never give information ‘off the record’ during or after interviews.
- Although it can be difficult, always try to substantiate your comments, providing sources if possible – this means some preparation beforehand.
- Don’t be tempted to provide answers that you don’t have – reporters may try to get you to say something ‘controversial’. You can always say, ‘I can’t comment on that’. Always refer back to the issue at hand: ‘I’m here to discuss …’.
- Provide the reporter with written material and/or the names of others to contact for background material, if appropriate.
- Have one or two supporters present while being interviewed.
- Keep the interview on track.

Responding to the media

In their eagerness to provide the public with ‘sensational’ stories, people in the media often give misleading, inaccurate and incorrect information. The group needs to have a mechanism in place to monitor what the media are saying or writing. When negative stories appear, immediately contact the appropriate person (from the list previously prepared). Ask for a meeting to discuss the group’s objections to the story and how the group can help the media outlet avoid presenting such negative stories in the future. It’s unwise for a single person from the group to go alone to the meeting. Rather a group of three or four who are knowledgeable on the issue need to attend the meeting. This can be included in the development of the media plan.

Media releases/press statements

Groups often use media releases to bring major issues to the community’s notice, or to just generally inform the community of some specific activity the group is currently involved in. There is no reason why small groups can’t do the same, especially if they network with other similar groups. Media releases need to be succinct, informative, and in some way stand out from all the other releases media outlets have to choose from. Media releases need to provide answers to six basic questions:

- **Who** is involved – who said or did what; to whom did it happen?
- **What** is going to happen or has already happened?
- **When** will or did the particular issue occur?
- **Where** will or did it occur?
- **Why** will or did it happen?
- **How** will or did it happen?
Suggestions for a media release

- Use standard A4 paper – if the group has a letterhead, use that,
- Write MEDIA RELEASE and a title for the media release in the centre at the top of the page,
- Double space the text and repeat the title on every page,
- Limit the media release to one or two pages (one preferably),
- Make sure that names and phone numbers of group representatives are provided,
- If using more than one page, don’t split sentences or paragraphs between pages,
- Ensure that the message is clear and understandable to the general community, for example, don’t use abbreviations or jargon,
- Add a ‘human dimension’, as long as it doesn’t detract from your main message,
- Use direct quotes from people,
- Be succinct while covering the issue – have no more than three key points and make them stand out,
- Follow up the media release with a phone call to the reporter.
The print media – newspapers

The media form most accessible to community groups is newspapers, especially local community newspapers which are often delivered free to every home. Not only is wide coverage guaranteed, but these community newspapers are more likely to print your material as a contribution to the community. Because of this accessibility, this section only specifically covers newspapers and concentrates on two ways to get material published in them: through letters to the editor and by submitting articles. It needs to be noted that many of the skills discussed below can also be applied to other print media (such as magazines). Some of the broad ideas can also be applied to radio and television.

Letters to the editor

All newspapers, including local community ones, have a regular ‘Letters to the Editor’ page. This is a common method for individuals and groups to have their say on particular issues. People often have the mistaken belief that newspapers automatically publish letters sent to them, and get a little upset when they don’t. Newspapers get hundreds of letters and somehow have to decide which ones to publish. They also have to decide how the letter is going to fit into the available space and it it needs to be changed or cut down (edited) before it is printed. The important thing is that the editing should not alter the meaning of the letter. If you find that it does, you have grounds for complaint. Some newspapers consult the writer first before editing.

To maximise your chances of having your letter published with as little editing as possible, read the instructions on the ‘Letter to the Editor’ page before you begin, note the style required and the desirable length of letters. If you have any doubts, ring the newspaper and ask to speak to the appropriate person.

Your letter has a better chance of being published if it:

● Is clearly worded and understandable,
● Relates to a particular issue that the newspaper readers are likely to be interested in,
● Is typed or carefully handwritten,
● Conforms to the style and length requested,
● Responds to a current issue reported in the paper – in this case, the letter needs to be sent as soon as possible, not longer than a few days after the issue was published,
● Does not contain any offensive or abusive language,
● Is not only negative but offers positive alternatives.

If you desire confidentiality, you need to specifically request this. Most newspapers require your name, full address and phone number for verification purposes, although only names and suburbs are generally printed.
Submitting your own article for publication

If you are responding to what you consider are inaccuracies in some article or editorial in a newspaper, there are several points to keep in mind. It’s important to clearly distinguish between the **facts** reported inaccurately, **omissions** of what you believe is relevant and **opinions** with which you disagree. Newspapers will (or should) acknowledge errors of fact or omissions. However, they will (or should) allow any person their right to an opinion, however ‘wrong’ you may think it is.

The most effective response to articles which you disagree with is to offer an article of your own. Some newspapers, especially local community ones, reserve space for such comment beyond the ‘Letters to the Editor’ section. The advantages of publishing your own article are length, substance, detail and prominence. Generally, articles of around 500 words are accepted. There is, of course, no obligation for a newspaper to actually print your article. If it is printed, don’t expect it to appear as you submitted it as it may be edited after you have given it your finishing touches. The headline is chosen by a sub editor of the newspaper.

To maximise the chances of your article being published, and with as few changes as possible, the following points can be considered:

- Although you may be very angry about the article that has prompted you to write an alternative view, go about your work in a planned, rational and methodical way. Talk to others in the group and to others who have written such articles before.
- First, prepare a framework for your article. These are the main points that you disagree with (reactive) and the alternatives that you want people to read (proactive).
- Once you have a framework prepared you will be ready to calmly and logically state your arguments. Talk to the features editor of the paper to discuss your plans before you write the full article. They have information that you need to have, otherwise you may be wasting a lot of time and emotional energy. For example, they may be particularly interested if your comment relates to a topical issue or offers a fresh approach.
- Be prepared to negotiate any changes and cuts to your article. (Also see 1.6: Interpersonal communication.)

References

5.6 Lobbying

Lobbying is an important strategy for sustaining effort and obtaining support in advocacy. It is something everybody can do, but it does require a little bit of research and a lot of persistence. Traditionally, lobbying referred to attempts to influence government legislation through communication with politicians or government officials involved in the formulation of legislation. This is sometimes referred to as ‘direct lobbying’. The word ‘lobbying’ comes from the word ‘lobby’ which, in legislative buildings, is the hall open to outsiders as well as to members. ‘Lobbying’ is the frequenting of this lobby to influence votes on legislation. Of course, people don’t have to attend these buildings anymore, as they can lobby through a number of ways.

Direct legislative lobbying includes the following factors:
- Lobbying must refer to specific legislation, for example, *Criminal Law (Sex Offenders Reporting) Bill, 1997* section 3(1)(b),
- Lobbying must reflect a view on this legislation,
- Lobbying must propose a course of action for the legislators.

The specific legislation can refer to present laws, or to specific legislative proposals that the individual or group either supports or opposes. Direct lobbying also occurs when individuals or members of groups and organisations individually contact legislators and government officials to support or oppose legislation. The individual or group may also want to attempt to influence the general public at election times, pointing out specific legislation the group either supports or opposes. This can also be considered direct lobbying. Grass roots lobbying is an attempt to influence specific legislation through efforts to affect public opinion.

Lobbying is the process which involves making the individual’s or group’s needs known. It is a communication and negotiation process which involves many of the skills included in this Kit. (Also see 1.6: Interpersonal communication and 1.3: Assertiveness.)

Successful lobbying involves developing a plan of action and allocating time, resources and people to follow that plan. It’s hard work but if the individual or group does not give up, if the request is a reasonable one or it is for an entitlement, there is a good chance of success.

There are a number of policy documents which detail what consumers and carers may expect. The following are examples of some of these documents:
- Commonwealth and State Disability Services Acts,
- Mental Health Acts,
- National Mental Health Plan,
- State Mental Health Plans,
- National Standards for Mental Health Services.
While, strictly speaking, lobbying is to do with legislative matters, the process of lobbying can really can be carried out with a range of organisations. For example, you may wish to lobby the media for changes to their policies and the enforcement of standards of reporting. The skills used in lobbying are the same no matter who you are lobbying.

Examples of lobbying can be:
- Getting people to support you,
- Getting people to speak on your behalf,
- Getting people to fund your project,
- Talking to important people so that they can influence other important people to speak for you,
- Keeping up good relations with people whose support may be needed sometime.

Lobbying can be conducted through:
- Face-to-face meetings with the relevant people,
- Telephone discussions,
- Faxes and/or e-mail correspondence,
- Letters,
- Enlisting the support of influential others,
- Appealing to the general public.

**Hints for lobbying**

- Develop a lobbying plan.

  A plan details how to conduct lobbying. It may be that the lobbying is only one part of a wider campaign. Specify exactly what is being lobbied for or against. Decide on a clear statement of the reasons for objecting to, or supporting, the issue or piece of legislation. Finally, propose a particular course of action for the lobbying target to take: in other words, provide an alternative.

  Once this is done, decide on the best strategy for lobbying. This may be different according to the lobbying target. It may be that face-to-face meetings with the relevant people may be sufficient. It is quite likely that a combination of letter writing, telephoning and face-to-face meetings are required. The plan needs to be flexible to allow for various situations. For example: ‘We will begin with a face-to-face meeting; if this is unsuccessful, we will write a formal letter; if this is unsuccessful, we will enlist support from other individuals and groups and request assistance from influential people who may support us’.

  Finally, the plan needs to provide guidelines for privacy and confidentiality, as some people may wish to remain anonymous in their lobbying activities. With guidelines in place and followed, individuals can still say a lot, with passion, and without overstepping boundaries.
- Find out who the key person is to lobby. Much time, energy and resources can be lost through lobbying the wrong person. For example, lobbying may be directed at the local mental health manager for the establishment of an ‘Extended Hours’ service in your area. It may be that this person has no power or influence to provide such a service. The appropriate person to lobby in this case may be the State manager of mental health services who controls the distribution of funds to local mental health services.

**Note! Finding the right person to lobby can be difficult.** People can be very good at ‘passing-the-buck’: ‘I would love to help but it’s completely out of my hands – you need to contact …’. When this occurs, go directly to the top person and find out who is responsible. If this person refuses to accept responsibility, let them know that the ‘top person’ will be told.

- Ring the key person and ask to be sent information on the issue in question. Gather as much information as possible on the issue. This is needed to make informed choices about the focus and extent of the lobbying efforts.

- Make an appointment to visit the people being lobbied. Discuss the lobbying issues with them and ask their advice. Get them involved if at all possible. For support and unity, attend the appointment with two or three supporters or members of the group.

- Invite them to attend a group meeting to show how informed and determined the group is.

- Follow up with regular phone calls.

- Ask advice from other people about who to lobby, and involve these people in the lobbying efforts.

- Get VIPs to write letters of support and attach them to letters sent to the people being lobbied.

- Members of other community groups can also offer support. Keep them informed too. Include a report of progress in their newsletter. Encourage their members to send letters of support to key people. Write a standard letter and request them to sign it.
Lobbying by phone

Lobbying by way of the telephone can be very effective because of the direct communication with the people being lobbied.

Before making a call, have written notes beside the phone to make sure that all the points are covered. Write down notes of what the other person is saying. It’s also a good idea to clearly inform the person when the next call will be made to indicate some deadline for action. Lobbying by telephone, however, can also present difficulties. Below are some tips on what to do if there are problems:

● **If they don’t call back** when they said they would, call them again and keep on calling. Don’t hang up or give up. Ask specific questions, and demand answers (politely but persistently).

● **If you’re getting no help**, detail all phone calls in a letter and send it to the head of the organisation being lobbied. Complain about the failure of the person to respond to requests and/or to provide the information requested.

● **Important!!** Always keep a written record. List all phone calls. Write down the time, the date, the name of the people spoken with, what you asked for and what their responses were.

Lobbying through letters

Letter-writing can also be effective, but, because the communication is not direct, it may be more difficult for the person being lobbied to fully understand the aims and objectives.

When writing letters be specific and word the letter clearly. Leave the reader in no doubt as to the specific issue referred to, your views on the issue and how you want to see the issue resolved. The following format may be useful in planning the structure of the letter:

● What is the issue?

● Why is it important?

● What are your facts, or beliefs about the issue?

● What are your rights with respect to this issue?

● What result do you want from writing about the issue?

● What positive results will happen if you get what you want?
Examples of key people to lobby regarding mental health issues

Politicians

- Federal Minister for Health
- State Minister for Health
- Ministerial advisors
- Opposition Leaders and shadow Ministers
- Local Members of Parliament
- Local Members of City/Town Councils

Administrators (mental health)

- National Director of Mental Health
- State Director of Health
- State Director of Mental Health Services
- People who assist the Director of Mental Health Services
- Regional Director/Manager of Mental Health Services
- Regional Director/Manager of Health

Mental health consumer and carer organisations

- State Consumer Advisory Group (CAG)
- National Community Advisory Group (NCAG)
- Local consumer and carer groups

Community organisations

- They are all the national, State and local community organisations involved in mental health issues.

Other public service bureaucracies

Heads of Departments in related areas, such as:

- Department of Health and Family services
- Department of Housing, Local Government and Planning
- Department of Social Security
- Department of Aboriginal and Torres Strait Islander Affairs
- Department of Employment, Education and Training
- Regional heads of service
- Local field officers
Developing a campaign

Consumer and carer participation is about making changes. In many instances, people find themselves concerned with a single issue or a particular set of issues. If you and/or your group find yourself planning a campaign, there are a number of things you need to do.

Identify the players
You need to explore your people resources: find out who is interested in becoming involved. Get together the individuals and groups who will actively participate in the campaign.

Identify the goals of the campaign
Next you need to consider some questions:

- **Why is the campaign needed?** The answer may be: numerous complaints from consumers about a particular regional service; the closing-down of a service; a change in the eligibility criteria for using a service or reduction of services due to funding changes. Or there may be national issues like the ‘capping’ of the number of visits to a psychiatrist, or the removal of certain medications from Pharmaceutical Benefits.

- **What change is required?** The answer may be: implementation of better complaints and feedback mechanisms in the particular service to ensure that problems are addressed; reopening of a service; reassessment of changes to eligibility criteria or redistribution of funding.

- **Who is your target ‘audience’?** The answer may be: regional service administrators, regional service providers, State or Federal parliamentarians and bureaucrats or others.

There needs to be agreement among campaign participants about these aims and goals. There also needs to be agreement about who will undertake what tasks in preparing and conducting the campaign. A group involved in a campaign needs to make sure that all its members are supported and clear about what is expected of them. The group needs to have regular meetings to check on progress and discuss problems as they arise.
Gather information – research the area

Key questions to help with your research include:

- **What information is needed to have the complete picture?** It is particularly important to have a thorough understanding of the issues before beginning your campaign. If you have not done this basic homework you will find your case dismissed out-of-hand.

- **Who are the key contacts?** These include, for example, consumers and carers using a service that has been the subject of complaint or criticism, or has closed down. Other key contacts might be the people running the service, that is, senior administrators or members of State government departments.

- **Who are possible supporters and allies?** Consumer and carer organisations may be able to provide information and support to help your campaign. There may be allies in unexpected places. You may find that the problems being researched are due to cuts in funding; in this case the people working in the service may well be just as concerned as service users about the standards of care. Opposition State and Federal members of parliament might also be useful allies.

Identify and gather resources

Key areas to assist with planning are:

- What financial resources are needed?
- What are the possible funding sources (such as donations, fundraisers)?
- What human resources are needed? What kinds of expertise do you have within the group? Do you need to recruit people with particular expertise?
- What infrastructure/equipment/resources are required?

For each campaign these resources are going to be slightly different, but an example of the kinds of basic equipment needed (which, of course, has implications for financial resources) are:

- A work area,
- A computer (or word processor, typewriter or someone who is happy to do a lot of handwriting),
- A telephone situated in your main work area, and the means to pay the phone bill,
- A fax machine and access to e-mail can be very handy,
- Stationery, including fax paper, computer or typing paper.
Plan strategies, tactics, activities

Major areas to address are:

- **What is the time frame for the campaign?** If you have a very short time to carry out your campaign, you need to consider what strategies are likely to be the most direct and effective.

- **What are the possible scenarios and what are the possible responses?** Do you expect to be given a hearing? If not, you need to reconsider your approach to the issue. Are you (as a group) interested in compromising on any of your ‘demands’ and prepared to negotiate a solution?

- **What are the different levels of activity and when is it appropriate to escalate activity?** Making decisions about these depends very much on responses you get from your target audience. For example, an invitation for the major interest groups to meet might mean that some activities will be put on hold or scaled down. A negative response to the invitation, or no response at all, may call for an escalation of activity.

- **When will the mass media be involved?** The group needs to decide on this one. Remember that media coverage has both good and bad consequences. Think carefully about how much or how little control you will have over the way your concerns may be represented in the media. (Also see 5.5: Working with the media.)

Implement plan

- What steps will you follow to put the plan into action?

- How will you continually monitor progress and developments? The importance of good communication between those involved in the campaign cannot be overstated.

Review and evaluate

- When and how will you evaluate progress?

- How can you adjust or alter strategies, tactics and activities to respond to developments?

- How will you gather information about audience reactions and responses to the campaign to date? What sort of information will this be?

- How will you use this information (feedback) to inform the campaign’s future directions/options?
Follow-up

● How will you make sure that, after it has ended, a complete record of the campaign is kept? This task can be made simpler by having someone within the group take responsibility for record-keeping from the start. Keep copies of all documentation: actions taken; meetings; media items and so on.

● How will you maintain and further develop contacts and networks that have been generated through the campaign process? You may find that, after your campaign is over, some or all group members are keen to undertake further related work. It is important to maintain useful contacts and to make sure that everyone who has helped in any way is thanked. (Also see: Engaging networks and organisations in the Knowledge and Attitudes Booklet.)

● What action, strategies need to be followed-up to make sure that any gains made are not eroded? This follow-up is particularly important. There are numerous examples of successful campaigns whose achievements have gradually been whittled away. Consumer and/or carer organisations, including advocacy groups, can be helpful in ‘keeping tabs’ on the area of concern. In addition, staying in touch with your original informants and allies may be useful. (Also see: Some forms of consumer and carer participation in the Knowledge and Attitudes Booklet.)

References

This glossary has key words which are particularly useful or which have been used in a specific way in the Kit. The inclusion of a word in the glossary does not imply that it is ‘preferred’ or that it should be used; it simply provides an explanation for the word.
Glossary of terms

abstract: a brief outline of a presentation (paper or workshop) to be given at a conference; a summary of a manuscript to be submitted for publication in a journal or book. An abstract for a conference presentation might be about 100 words; for a longer piece, it might be up to 500 words or more.

accountability: liability, answerability; a requirement to account for one’s actions, writings, expenditure, usually in the context of a position of responsibility one occupies.

advocacy: promoting and/or supporting a cause, such as consumer/carer rights to services, information, basic human rights; used in a broad sense in this Kit to refer to a wide range of activities engaged in by consumers and carers in promoting and supporting their causes.

advocate: a. (noun, as in, ‘John is my advocate’): a person who actively supports another person’s cause. b. (verb, as in, ‘I advocate that consumers and carers should be involved in evaluating the program’): to provide active support to another person’s cause.

self advocacy: what an individual does to represent his/her own needs/rights.

peer advocacy: the activity undertaken by more than one person to represent the needs/rights of his/her peers (that is, consumers addressing the needs/rights of other consumers).

systems advocacy: those activities directed specifically towards the systems, structures and forms that are instrumental in the conditions that create injustices and inequities.

altruism: goodwill; doing something without thought of reward or recompense, that is, doing a ‘good deed’ without an ulterior motive.

anonymity: namelessness; without recognition; the state of being unidentified.

arbitrator: usually a neutral ‘umpire’, mediator, or go-between; someone who is able to make independent decisions in a situation where various different viewpoints are being discussed.

auspice: the medium or agency (usually an organisation, private or public) through which a project or program is carried out. This is different from provision of funding and has more to do with provision of infrastructure such as office space, an address, phone access and, perhaps, conferring greater status to a particular project.

billet: lodgings; staying in someone’s home as an alternative to motel/hotel accommodation.

bureaucracy: officials who work within government. ‘Adminstration’ is sometimes used instead of ‘bureaucracy’.

carer: people close to (often living with) someone who lives with mental illness/distress. Includes ‘family carers’ and friends or allies who offer support in times of need. Many people ‘care about’ what is happening to a friend or relative but do not identify with the term ‘carer’.
carer perspective: a way of seeing the world through the eyes of someone who has experienced the role of ‘caring about’ a person who lives with mental illness/distress. Includes a recognition of the emotional strain and despair of seeking appropriate services and support for oneself and for a loved one. Also includes a feeling of solidarity with others in the same or similar situations, and a determination to bring about improvements.

case manager: a service provider with the responsibility to coordinate treatment, support and backup services for individuals.

chairperson/chair: a person who heads a committee (or similar formal group), and is responsible for ensuring that meetings are orderly and topics listed for discussion are addressed.

community development: a range of activities that promote a whole-of-community approach, with empowerment and social justice as key principles.

community education: usually takes the form of some kind of organised campaign to increase people’s awareness and understanding of a particular issue or set of issues. A campaign might include advertising in the media; distribution of pamphlets; appearances on radio and TV talk shows; talks and workshops run for school students and others.

community visitor: a person who visits consumers in service settings (mainly hospital) to monitor their wellbeing and/or carry out personal advocacy. A community visitor or similar scheme exists in most States and Territories, either paid or voluntary.

confidentiality: privacy of certain information and how information is stored and used. (Also see: The challenges of advocacy in the Knowledge and Attitudes Booklet; 3.2: Telling stories; 3.4: Attending conferences; 5.5: Working with the media, for detailed discussion of the meanings and issues around confidentiality.)

constituency: the group of people who are represented by those elected as their representatives.

content: the issues which are under discussion and for which decisions will be made (contrast to ‘process’).

consultant: a. a person who consults others, gathers their views and provides advice based on the experiences and knowledge gathered from this wide and diverse source. b. a person considered to have expert knowledge who uses this expertise to assist those who consult him/her.

consumer: any person who has experienced mental/emotional distress and who has received services – whether or not they are still receiving those services – and any person who has experienced mental/emotional distress and who has been refused services.

consumer perspective: a way of seeing the world in the light of experience/s of mental/emotional distress. Includes experiences of seeking support (of various kinds), of stigma in the community and within services. Also incorporates a sense of solidarity with others who have had similar experiences.
convenor: a person responsible for organising a meeting, conference, workshop; a person responsible for bringing people together for a specific purpose.

curriculum committee: a committee set up to discuss and decide what will be taught and how it will be taught in an educational institution.

debriefing: the act of discussing or talking through a recent experience, such as a crisis of some kind, a presentation, experiences at a conference or committee sitting.

Deep Dialogue: a structured sharing of views, experiences and opinions around mental health issues within a small group. The important ingredients are that the group includes a range of individuals with differing experiences and that group members are respectful of each other’s contributions.

deferential: respectful; obedient.

deurstitutionalisation: often used (over-simply) to describe the process by which individuals who have previously received services in a ‘hospital’ or ‘home’ are moved out of that place into the community. Also includes the process by which those individuals need to ‘unlearn’ a whole set of behaviours and expectations that have been acquired during their institutional lives. The political/social process of ‘deinstitutionalisation’ should (but in the main has failed to) include adequate provision of services, housing and other supports ‘in the community’.

empowerment: used to encapsulate a complex set of issues around an individual’s subjective and objective experience of the world, his/her position in it and his/her ability to undertake certain things. No one can ‘empower’ another person, but individuals, institutions, systems, social traditions and practices can and do disempower individuals and groups of individuals. When an individual is empowered, he/she feels able and strong enough to make decisions about his/her life; to ask questions rather than blindly accepting the opinions of others who hold greater status; to make mistakes and to enjoy successes.

enabling: the process by which empowerment occurs.

equity: an abstract principle that applies to deciding relative fairness. Advocacy activity is often aimed at ensuring that equity is established and maintained.

evaluation: assessment; appraisal; examination; judgment of the worth of something. (Also see: The mental health system in the Knowledge and Attitudes Booklet and 1.10: Family involvement in service delivery to consumers, for further discussion.)

facilitator: a person who works with a group to assist it to make decisions and achieve outcomes by focusing on the process (see ‘process’) of group discussion and decision-making. A kind of leader, who doesn’t get involved in the content (see ‘content’) of the discussion.

feedback: information, opinion, commentary, revision received from concerned individuals or groups in response to a proposal, project, process that has repercussions for that person or group. Feedback can be verbal or written, formal or informal.

incorporation: the legal process of developing a group or organisation into a legal corporation.
jargon: technical or otherwise limited/specific terminology; a kind of ‘slang’. Different professional and other groups use certain kinds of words that have little or no meaning beyond the context of their area of expertise. While most people use jargon to some extent, medical, bureaucratic, scientific, psychological or other jargon can be used in a way that alienates and disempowers consumers and carers.

justice: an abstract principle that applies to deciding the fairness and appropriateness of actions. Advocacy action is often aimed at ensuring that justice prevails.

lobbying: representing particular interests to others to influence the outcomes.

mainstreaming: the process of integrating mental health services with health, housing, social, welfare and recreational services for the general community, with the aim of reducing stigma and providing an appropriate range of services.

media: channel for mass communication of information to general and/or specific audiences (electronic media – radio, television, film; print media – newspapers, magazines).

mediator: a person who acts as a go-between to settle conflicts or disputes. A mediator should have no connections with those involved in the dispute and have no vested interest in the issues or outcomes.

medical model: an approach to mental health problems based on medical assumptions that ‘abnormal’ thoughts and behaviours are mental illnesses which can appropriately be controlled by medication and hospitalisation, not unlike physical illnesses.

mental health professionals: generally describes professionally trained people working specifically in mental health, such as social workers, occupational therapists, psychiatrists, psychologists and psychiatric nurses.

mental health promotion: activities which promote positive stances towards mental illness, mental health and people experiencing mental health problems.

mentor: a person who, through their knowledge and experience, acts as a trusted personal advisor for another.

networking: (jargon) getting to know and connecting with people who may be helpful to one’s cause, career, task, project, organisation; developing a range of helpful contacts.

non-government organisation (NGO): includes charitable and other non-profit organisations not directly answerable to any government department, although some are wholly or partly government funded. Independence is an important attribute of NGOs which are usually concerned with such issues as human rights, legal rights, the environment, food and housing. Examples of high profile non-government organisations are Amnesty International and Greenpeace.

passion: a strong emotional feeling towards something.

philanthropic trust: a fund set up by an individual or organisation to distribute financial grants to those who fulfil its guidelines.

process: the manner in which issues are discussed and decisions made; a set of operations that are applied to specific issues (contrast to ‘content’).
**proactive**: carry out activities, put forward ideas in order to set the agenda (contrast to ‘reactive’).

**quality assurance**: processes and practices to ensure services and their means and manner of delivery are appropriate to the needs of consumers and carers. Includes ensuring that consumers and carers are listened to both individually and through representatives. Quality assurance requires that user-friendly complaints mechanisms are in place, and that decisions about mental health services and issues are not made in the absence of those who are most affected by them.

**reactive**: carry out activities, put forward ideas as a response to an agenda set by someone else (contrast to ‘proactive’).

**regional services**: within each State and Territory, public mental health services are organised into a number of regional centres, each responsible for the delivery of services within a particular area.

**representativeness**: the ability to reflect the views and concerns of one’s constituency.

**self advocacy**: people speaking out for themselves.

**self-identification**: the way that people identify themselves publicly and privately; people who have had consumer or carer experience, choosing to identify themselves as ‘consumers’ or ‘carers’ in their public lives.

**service provider**: includes nurses, psychologists, occupational therapists, psychiatrists, social workers.

**stakeholders**: the different groups that are affected by decisions, consultations and policies.

**status quo**: an unchanged position; the original position; the present political arrangements.

**stereotype**: ‘hackneyed’ image; conventionalised idea; cliche; typical presentation.

**stigma**: disgrace; shame; disrepute; infamy; reproach; blemish; blot; stain; taint.

**symposium**: seminar; discussion; debate.

**systems advocacy**: any advocacy activities designed to bring about system-wide changes rather than changes to the circumstances of an individual. (Also see: Undertaking advocacy and The challenges of advocacy in the *Knowledge and Attitudes* Booklet for more detail.)

**validation**: process of determining the correctness of some proposition or conclusion.

**workshop**: seminar; instruction session; educational gathering; discussion group.
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The following index assists you to locate all the major references made in the Kit to a particular topic.

**NOTE:** The page numbers refer to the numbered pages in *Skills, Strategies and Tools* unless they are preceded by the word ‘booklet’ in which case they refer to page numbers in the *Knowledge and Attitudes* Booklet. For example:

- **Brainstorming, 181** [means material about brainstorming is on page 181 of *Skills, Strategies and Tools*].
- **Advisory groups, booklet 15** [means material about advisory groups is on page 15 of the *Knowledge and Attitudes* Booklet].
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