

Guidelines

for

Community Support Advocacy



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Community Support Advocacy

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1. Introduction

Advocacy is an action or actions that assist individuals or groups to achieve and maintain their rights. When we build advocacy skills we become better equipped to deal with problems and conflicts. These can be our own or those of others who seek to share a complaint or issue with us.

Help from another person – relative, friend, advocate – can relieve the emotional vulnerability many people feel when dealing with a problem situation in the health system, as well as assist to guide the person through the complaint processes. However, stepping in to help another person with their personal health issue needs to be done with sensitivity, skill and caution.

This manual, and the associated program, aims to provide potential community advocates with the information and skills to assist a health consumer with a complaint or problem. The manual is designed to give health consumers the information, skills, tools and resources to advocate on behalf of themselves and to assist others in the community in dealing with problems they face in the health system.

The goal is to increase the likelihood of a fair and equitable outcome to the situation with as little stress and conflict as possible.

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To everyone involved in this project – my very special thanks.

Anne Atkinson, BA (Hons) PhD

Advocacy

2. Understanding Advocacy

a) What is Advocacy?

Advocacy is an action or actions that assist individuals or groups to achieve and maintain their rights.

Advocacy can also be described as:

`the pro-active promotion or support of a cause, such as the right to a service, the right to information, the right to basic human rights, the right to redress...'

and

`standing by someone'

and

`creating choices for people beyond submission or resistance'

Health Consumer Advocacy

Health consumer advocacy is any activity undertaken by individual health consumers or groups of health consumers to influence the way that health services are delivered. In the past few decades, changes in community attitudes towards traditional structures of power in the health system, such as the dominance of doctors, hospital administrators and health bureaucrats in determining health policies, have resulted in the creation of health consumer bodies in challenging these structures. One aspect of this is the inclusion of health consumer representatives on committees and working parties concerned with reviewing and developing health policies.

b) Why is Advocacy Needed?

There are occasions when health consumers may feel that they have been unjustly treated or face difficulties in the health system. Sometimes

consumers can deal with these problems themselves, sometimes they may need the help and support of others and sometimes the issues of concern are so common to consumers that the health system itself may need to change.

These situations may arise due to:

- the way in which health services are organised;
- the complexity or rigidity of the health system;
- the barriers to contacting the right person to speak to in the health system;
- the manner or attitudes of service providers;
- the problems associated with the illness or injuries the consumer is dealing with.

Overarching all of these is the recognition of **power imbalances** between service providers and consumers.

Advocacy not only addresses the injustices and difficulties consumers may have within the health system, but it also contributes to learning and improving health services for others in the future.

c) What is an Advocate?

An advocate is someone who:

- Speaks up for themselves to achieve and maintain their rights;
- Actively supports another person's cause through a thorough knowledge of that person's rights and entitlements as well as being familiar with the process of addressing situations of injustice;.
- Seeks to change systems to reduce or eliminate structural inequalities and injustices.

3. Consumer Rights

In order to be an advocate, either for yourself or to assist others, it is essential that you are familiar with the *rights* and *responsibilities* of a health consumer in Australia. Without an understanding of these *rights*, it will be impossible to know what you are entitled to, how far you can challenge the

system when you feel it has let you down, or to assist others in redressing situations they feel need changing.

There are three sets of rights.

- The first set - *Eight Consumer Rights* - relates to your *rights* as a health consumer in general.
- The second set relates to your *rights* as a patient in the public hospital system in Western Australia.
- The third set is a more detailed listing of *rights* identified by the Health Consumers' Council.

Eight Consumer Rights

1. *The **right** to satisfaction of basic needs* – food, clothing, shelter, health care and education.
2. *The **right** to safety* – protection against products, production processes and services which are hazardous to health or life.
3. *The **right** to be informed* – given the facts needed to make an informed choice and be protected against dishonest or misleading advertising and labelling.
4. *The **right** to choose* – to select from a range of products and services offered.
5. *The **right** to be heard* – to have consumer interests represented in the making and execution of government policy and in the development of products and services.
6. *The **right** to redress* – to receive a fair settlement of just claims, including compensation for misrepresentation, shoddy goods or unsatisfactory services.
7. *The **right** to consumer education* – to acquire knowledge and skills needed to make informed, confident choices about goods and services, while having an awareness of basic consumer rights and responsibilities.

8. *The **right** to a healthy environment* – to live and work in an environment that is non-threatening to the well being of present and future generations.

from 'Guidelines for Consumer Representatives', CHF, 1999

Patients' Rights in Public Hospitals in Western Australia

Patients in public hospitals in Western Australia have:

1. The **right** to choose to receive quality public hospital services as a public patient free of charge, or as a private patient;
2. The **right** to receive services on the basis of clinical need, as promptly as circumstances permit regardless of financial or health insurance status;
3. The **right** to be treated with respect, dignity and consideration for privacy and special needs;
4. The **right** to have access to a basic range of public hospital services regardless of where you live in Western Australia;
5. The **right** to be given a clear explanation of any proposed treatment including possible risks and alternatives before agreeing or refusing to have the treatment;
6. The **right** to seek a second opinion;
7. The **right** to be given information about continuing health care before you leave the hospital;
8. The **right** to see your medical records, subject to some legal provisions, and to have personal information kept confidential;
9. The **right** to agree or refuse to participate in health professional training or medical research;
10. The **right** to comment or complain about the health care you receive and to be given information about how to lodge a complaint.

(Department of Health WA, 2002)

Patients' Rights in Private Hospitals

The Australian Government Department of Health and Aging has published a Private Patients' Hospital Charter. The Charter is a guide to what it means to be a private patient in a public hospital, a private hospital or a day hospital facility. It also sets out what consumers can expect from:

- * the doctor(s) providing treatment
- * the hospital in which treatment is provided
- * their health insurance fund.

In addition, the Charter provides information on what to do if you have a complaint about the standard of care you received or private health insurance. Further information can be obtained from:

<http://www.health.gov.au/internet/wcms/publishing.nsf/content/privatehealth-hospital-charter-contents.htm>

(Department of Health and Aging Website, 2006)

Health Consumers' Council (WA) Consumers' Rights

- Be treated with care, consideration and dignity
- Be given clear information and explanations
- Ask questions about the service, to make sure you are clear about what it offers, who is eligible, what costs are involved and what are your responsibilities
- Ask questions about any issue pertaining to your health care and discharge care, arrangements, proposed treatments or procedures, full disclosure of all associated risks of treatment, alternative treatments, costs
- Be given time to take in and understand the information provided
- Be informed if the proposed treatment or procedure is experimental or part of medical research
- Obtain assistance from trained interpreters if required

- Ask to be referred to a more senior person if you are not happy with the quality of the service provided, obtain a second opinion (except where this is not possible, for example, in an emergency)
- Give your informed consent before treatment begins
- Withdraw your consent and refuse further treatment (except in certain circumstances)
- Appoint someone to make decisions on your behalf if necessary
- Leave the hospital at any time, except in the case of some infectious diseases and psychiatric conditions. (If you leave the hospital against medical advice you will need to sign a waiver to say you are responsible for your own illness or injury and will not hold the service provider responsible).
- Confidentiality of all personal records (except where the law requires that information be given to some person or authority).
- Have access to your medical records in the public sector through the Freedom of Information Legislation and in the private sector through the *Privacy Amendment (Private Sector) Act, 2000*.

Health Consumers' Responsibilities

While health consumers have rights, they also have responsibilities. These include:

- Treating staff with care, consideration and dignity;
- Considering the comfort and needs of other patients;
- Asking questions about the service and your treatment, and keep asking questions until you fully understand the issue;
- Giving the service all the information about your health (including special needs including cultural and religious needs) to enable health workers to give you the best care and advice;
- Telling staff if you are unable or don't intend to follow your prescribed treatment plan;
- Telling staff about changes in your health, including any problems you may have with the treatment you are receiving; and

- Keeping appointments or letting the service know if you are unable to attend.

An information booklet for all Western Australian health consumers, called *Patient First*, has been produced by the Department of Health. The Patient First program provides information about patients' rights in relation to their health care. Copies should be available in all hospitals in the state. The booklet and the related DVD can be obtained from the Office of Safety and Quality in Health Care whose contact details are:

Telephone: (08) 9222 4080

Email: safetyandquality@health.wa.gov.au

Website: www.health.wa.gov.au/safetyandquality



4. Types of Advocacy and the Roles of Advocates

There are many definitions of advocacy and there are different ways in which advocacy can be carried out. The Health Consumers' Council is generally concerned with four types of advocacy:

- Self-advocacy;
- Community support advocacy;
- Systemic advocacy; and
- Professional or individual advocacy.

This manual will focus on the skills and knowledge required to carry out community support advocacy. However, it is not easy to separate all forms of advocacy as they overlap significantly. For example, without individual and community support advocacy, it would be very difficult to implement systemic advocacy. As you become more familiar with the various forms of advocacy, you will see the similarities and differences and how they work together.

Advocates Roles

a) Self-Advocacy

Self-advocacy is acting on behalf of yourself to ensure that your rights and interests are respected. Self-advocacy involves:

- Speaking up for **yourself**
- Knowing **your** rights and responsibilities
- Making choices and decisions which suit **your** circumstances
- Empowering **yourself**

The path of self-advocacy does not exclude external help if you feel you need it; you will still be making choices and decisions for yourself with the help from community advocates or professional advocates.

An Example of Self Advocacy

Annie needed a small surgical procedure that required her being admitted to the day surgery ward of a large city hospital.

When she arrived at the ward she was told to remove all her clothing and replace it with a hospital gown which was done up at the back with short ties. All gowns seemed to be the same size and, as Annie was a large woman, the same-size-fits-all gowns did not fit her at all, let alone provide adequate covering. She wished that someone had thought to include on the list of items to take to hospital – one dressing gown. She asked the busy staff if there was a solution to the problem but they responded that she was only entitled to one gown and that was all they had.

She might not have bothered too much but the day ward was an open ward that accommodated both men and women. To get from the change room she had to walk the length of the ward to her bed clutching the gown as best she could. She felt humiliated as she was aware of the eyes of all the other patients on her during the long walk. She was not alone as all patients, whether men or women, had to go through the same process.

While Annie was lying in bed waiting for her surgical procedure she thought on the problem and if she was entitled to make a complaint about the failure to maintain dignity and privacy. It seemed such a small matter in the scheme of things. She remembered a poster in the hospital foyer on the Rights of Patients in Public Hospitals and decided that when she left the hospital, she would check the poster. She did check the poster and noticed the third point; 'The right to be treated with respect, dignity and consideration for privacy and special needs.'

When she had recovered from her surgical procedure, Annie wrote a letter to the hospital outlining her experience in the day ward and making two suggestions. The first was that a dressing gown should be included in the list of items that were to be brought to hospital. The second was that a notice be placed in the change room informing patients that if they didn't have their own dressing gown, they could use two gowns: one to be tied at the back, and the other to be used as a dressing gown with the ties at the front.

Apart from receiving a letter from the Patient Liaison Officer at the hospital apologising that her experience in hospital was not as comfortable as it should have been, Annie was assured that both her suggestions had been taken up and were now part of hospital policy. Further, not only would the provision of two gowns be made

mandatory in the day ward, but also in radiology and other parts of the hospital which required patients to wear gowns in public places.

Annie felt pleased that not only was her experience taken seriously, but that her suggestions would make it easier and better for other patients.

b) Community Support Advocate

Community (support) advocacy occurs when a consumer, who feels their rights and interests have not been respected, seeks to redress the situation but lacks the knowledge, confidence or physical ability to do this by themselves. A community support advocate can assist, advise and support that person as they make their own choices about how they might best proceed in their advocacy actions.

A community support advocate differs from a professional advocate in one important way – a community support advocate operates outside the constraints of an organisation while a professional advocate operates within the boundaries of an organisation (in this case, the Health Consumers' Council). In many ways then, the community support advocate has more freedom to assist the consumer in matters not immediately related to the health issue but play a peripheral role. A community support advocate needs to:

- Have a strong understanding of the rights and responsibilities of health consumers and convey this to the person they are assisting;
- Listen well;
- Be aware of ethical considerations;
- Allow the person they are assisting to direct the process of advocacy;
- Take each step in the advocacy process one at a time and agree on each action; and
- Be assertive and strong when necessary.

An Example of Community Support Advocacy

After his father's death, James bought a small house in the metropolitan area with his inheritance and started living on his own for the first time in his life. A long-time friend of his age, Mark, saw how he was struggling to manage and set out with James to formulate a plan for the future.

The metropolitan house was sold and another bought and rented out in a country town. The balance of funds allowed for settling debts, buying a vehicle and a modest business. James also set himself up with new furniture and goods in a rented house.

At the time the plan was being put into effect, James came to the attention of Mental Health Services (MHS) due to his insomnia. However, on assessment there were issues other than insomnia that were identified by the Mental Health workers. They deemed his spending to be a symptom of a mental illness (mania) and applied to have his financial affairs placed under the Public Trustee.

Up until this point, Mark had been acting in the capacity of 'community support advocate', working co-operatively with James to help him to achieve his goals. With the MHS application to the Guardianship and Administration Board for an Administration Order for James' financial affairs, Mark needed to call in some help from professional advocates to challenge the application. [An Administration Order gives control of a person's finances to the Public Trustee or another person. This can lead to loss of skills in money management and control can be extremely hard to win back.]

The combination of Mark's documentation and statements, the professional advocate's rights advocacy and James' testimony on his own behalf, prevented an Administration Order being made.

The effect of removing control of his financial affairs for James would have been devastating and severely curtailed his independence. MHS made a negative judgement based on a snapshot of James' life.

Without Mark's support, before and after the involvement of mental health services, James' life would look very different today.

c) Systemic Advocacy

Systemic advocacy aims to change the way systems work, or the basis on which they work, through structural change or reforms for the benefit of consumers who use the systems' services and resources. A systemic advocate identifies areas within the health system that appear to be unjust or inequitable through information from consumers and adopts a range of strategies to bring about systemic change. These strategies can include:

- suggesting policy and practice changes and proactively driving these changes;
- strategic partnering (building coalitions and collaboration, sitting on committees and raising issues with relevant bodies);
- networking, community education and consultation to influence consumer expectations;
- public relations and using the media;
- using statutory bodies that have a systemic function (e.g. Equal Opportunities Commission, Office of Health Review, Office of Public Advocate);
- lobbying at political levels for legislative reform; and
- using the legal system as in a class action.

An Example of System Advocacy

Clare's cancer diagnosis and radical surgery came after her concerns had repeatedly been dismissed by doctors she consulted. She realised that widespread stigma and ignorance, amongst women and doctors, meant that other women could easily face the same horrible loss as her, if nothing was done to change the health system and inform women of risks.

In a state of anger and determination, Clare started to tell her story to people she thought may be able to help her to work out what to do. An article in a national women's magazine led to dozens of calls from women with like experiences. With this authority and the information from many stories, Clare began to define the problem, propose strategies and galvanise support from others. She established an organisation that supports women, educates the public and lobbies politicians, clinicians and decision-makers.

Clare's system advocacy has changed forever the way that this particular taboo topic is addressed in Australia, and to some extent, the world.

d) Professional Individual Advocacy

The work of the Professional Individual Advocate differs from that of a community support advocate in one principal way: the professional advocate works with the support of their organisation, a community support advocate works outside the boundaries of an organisation. The advantage of working within an established credible health consumer organisation is that the professional advocate has generally built up networks which can assist in the processes of advocacy, is more often taken seriously and is generally more successful in not being 'fobbed' off or ignored.

In addition, professional advocates are available to provide assistance to community support advocates when it is needed.

Some of the duties of the professional advocate include:

- talking through issues to clarify or define the main factors within the consumer's complaint;
- attending appointments with consumers and service providers in an advocacy (third party) capacity;
- writing letters, faxes or phoning service providers on behalf of consumers to assist in resolving an issue;
- providing resources to assist consumers in managing their own complaint;
- faxing or writing to providers on the Health Consumers' Council's behalf after a consumer has raised a general issue worthy of direct mention to the service provider;
- assisting to write up complaints to the Medical Board or the Office of Health Review;
- assisting Consumers' to access medical records through the *Privacy Amendment (Private Sector) Act 2000* and through Freedom of Information requests;
- visits to consumers in hospital or at home if medically necessary;
- attending lawyer's appointments with consumers; and
- other assistance as required.

An Example of Professional Individual Advocacy

A young man consults a physiotherapist who is also involved in his sports club. He attends for some treatment of a bruised shin. The physiotherapist notices tight calf muscles and offers additional treatment of a heat pack. The heat pack is too hot and causes third degree burns that result in skin grafts needed to repair the wound. The repair treatment and other expenses result in lost income from employment plus large out-of-pocket costs, despite payments from health insurance.

The professional advocate listens to the consumer's story for both facts and the feelings expressed by the person, to assess what it may be that the person seeks to achieve.

The first and fairest step to take is to return to the practitioner to seek an explanation and request redress (in this case reimbursement of costs). If the consumer feels confident about doing this themselves, either in writing or in person, the advocate can discuss how to go about this, including what to write or what to say at a meeting. If the consumer needs help with a letter, this can be provided.

In this case, the letter of complaint from the young man to the physiotherapist, was written by the advocate for him to send. The physiotherapist was not prepared to reimburse expenses and so the young man decided to seek legal advice. The advocate provided a list of lawyers who do medical negligence work and offered to attend the appointment with the lawyer, if this would be helpful.

e) What role can community members play in advocacy?

Community members play a crucial role in advocating for improved health services, whether it is in redressing injustice in a particular situation or encouraging systemic change. Community members can be active in:

- *Self-advocacy*

Anyone can speak up for themselves. All it takes is some preparation in finding out your rights and responsibilities as a health consumer, some knowledge of how the health system works and, most importantly, planning, confidence and assertiveness.

- Information on your rights and responsibilities in the health area is contained in this manual
- You can obtain information on the health system by going to the Health Consumers' Council website (<http://www.hcc-wa.asn.au>)

and downloading a very useful booklet, *Some Things You Might Like To Know About The WA Health System*, or contacting the Health Consumers' Council by phone on **1800 620 780** (toll free for country callers) or (08) 9221 3422 for a copy.

- Building confidence and assertiveness may seem a little daunting. Some people are naturally gifted; others work hard at attaining it. These are a few pointers which might help:
 - work out just what the problem is and how your rights and entitlements have been ignored. Write everything down so that you are best able to clarify the situation
 - plan the steps you are going to take to try to resolve the problem. This might involve such things as:
 - writing a letter about your problem to the person you think is the most relevant
 - making an appointment
 - making a request to check your medical file
 - Thinking of alternative plans in case your initial one hits a brick wall
 - Identifying what you would like to see as the outcome
 - Call for assistance from the Health Consumers' Council if you find it too difficult to do on your own.

Community Support Advocacy

Anyone can also be a community support advocate with a little knowledge and training. This manual will help you obtain the skills and knowledge needed to assist others with self-advocacy or to actively support others in obtaining their rights and entitlements and redressing difficult and often distressing situations.

In the next sections of the manual you will find information on the fundamentals of community support advocacy, the skills needed and the process of community advocacy as well as where to find additional help and resources.

Systemic Advocacy

There are many ways in which community members can become invaluable systemic advocates. Perhaps the most important requirement is a deep interest in health issues, a desire to remove injustice and an aim to see an improved consumer-centred health system. You might wish to contact the Health Consumers' Council and become a member. Membership will entitle you to regular updates and information on health issues through the regular newsletter and the opportunity to join various discussion groups. The Health Consumers' Council also provides regular training sessions for people who are interested in becoming health consumer representatives and be actively involved in systemic advocacy through:

- participating in focus groups and consultancies with other consumers on health policy and health related matters
- being involved in committees and Health Advisory Councils which deal with health issues (eg. local or regional committees and District Health Advisory Councils)
- assisting in training programs for service providers
- becoming involved in various Health Consumers' Council activities.

At an individual level, any person has the democratic right as a citizen to communicate directly with a politician and public servants to express a view or make a suggestion. This sort of lobbying can lead to system reform by keeping decision-makers informed about community views on issues and adding to the weight of lobbying from others. Temporary, single-issue groups, or established organisations, all contribute to systemic advocacy in their own way. Joining such groups is a way of being involved in an organised collective effort to drive change in a positive direction.



Community Support Advocacy

Before it was called `advocacy`, people did and still do step in to help family, friends and others as a `support person`, `carer` or `friend`. This activity is not new but calling this form of support `advocacy` adds formality, responsibility and authority to the role.

Community support advocacy involves supporting and possibly acting on behalf of someone who feels they have been badly treated or dealt an injustice within the health system. It involves developing a special relationship with the person you are supporting that involves trust, respect, humility, assurances and agreements, the establishment of explicit consent to undertake advocacy and the confidence and courage to challenge established authority.

To be a community support advocate and be invited to become involved in someone else's life at a time of stress and possible hardship is a privilege which cannot be abused through unethical conduct, dishonoured promises and disregard for the views of the person being assisted.

This section raises several issues you are invited to think about carefully.

5. Foundations of Community Support Advocacy

a) Attitudes and Values

One of the first steps in becoming a community support advocate is to examine your own attitudes and values. Ask yourself why you are becoming involved in advocacy.

The positive motivations for stepping in to be an advocate are usually clear. These may be due to the obvious need of the person and the absence of anyone else to help them, as well as knowing you have the skills and knowledge to tackle the problem as you see it.

However, it is also important to examine what could be negative motivations for you to take on an advocacy role. If negative motivators exist, it is vital to consider them, as they may cause problems later as your involvement deepens.

- Is it because you are assisting a friend or family member? Will this relationship cloud your ability to see the situation clearly? Will you focus on the detail instead of seeing the `bigger picture`?
- Is it because it presents an opportunity to confront `authority` because you have deeply held attitudes – consciously or unconsciously – towards various types of authority? Might these attitudes result in unwanted conflict that might damage `the case`?
- Is it because you see problems within the health system that **you** want redressed? Will this attitude result in **your** views taking precedence over those of the person you are assisting?
- Is it because you like to fix things for others and make it better? Will this approach enable you to best respect and represent the views of the person for whom you advocate?

There may be many reasons for you to wish to become a community support advocate so take a little time to see how your attitudes and values might influence the way you deal with your role as a community advocate and how they might differ from those of the person you are assisting.

Attitudes and values

Your attitude is an expression of your values, beliefs and expectations.

Brian Tracey

I am convinced that attitude is the key to success or failure in almost any of life's endeavours. Your attitude--your perspective, your outlook, how you feel about yourself, how you feel about other people--determines your priorities, your actions, your values. Your attitude determines how you interact with other people and how you interact with yourself.

Carolyn Warner

b) Humility, Modesty and Ethical Conduct

Central to being an effective community support advocate are the qualities of humility, modesty and ethical conduct.

In becoming a community support advocate, you are taking a supportive role in whatever the person needing assistance is aiming for. It is, therefore, **their** case, **their** views, **their** story, **their** life and **their** choices that should be uppermost in any dealings. You are, in effect, taking a back seat in carrying out their instructions, even if it is you who are making the appointments, writing the letters or doing most of the talking at meetings. You are still doing these tasks under the instruction and in total agreement with the person you are helping. Underpinning these objectives are the qualities of humility and modesty that allow us to respect the views, needs and values of others and see them as important as our own.

Humility

There is no respect for others without humility in one's self.

Henri Frederic Amiel

Modesty

What can be found equal to modesty, incorrupt faith, the sister of justice, and undisguised truth?

Horace

The modest man satisfies himself with peaceful silence, which all his companions are candid enough to consider as proceeding not from inability to speak, but willingness to hear.

Samuel Johnson

Ethics are a system of moral values and principles on which the rules and standards guiding the way we conduct a task or project are based. There

are two main ethical considerations to take into account when it comes to community support advocacy:

- Respecting and protecting any personal information about the person you are assisting. Trust is a key component of the relationship you build up and if confidentiality is broken, trust is lost and your ability to assist is damaged. Retaining confidentiality can be difficult in small communities where everyone knows everyone else, so it is even more important to be aware of disclosing any information without the clear and specific consent of the person you are assisting.
- Ongoing consultation with the person you are assisting at every step of the case. Remember that it is not your cause you are assisting with, but the person you are helping. It is they who have experienced the reason for their case and it is they who will have to live with the consequences of the outcome of the case. Therefore, at all times it is ethically fundamental that it is they who take control of the case and make decisions about what to do and when to do it. It is your role to assist, advise, give options, discuss strategies and tactics, support, and provide a shoulder. In the end, it is they who make the decisions.

Ethical conduct

A man is ethical only when life, as such, is sacred to him,... and when he devotes himself helpfully to all life that is in need of help.

Albert Schweitzer

c) Expectations and Promises

Your attitudes and values shape the expectations you might have of the types of advocacy actions you take and the outcome of the case. The person you are assisting will probably have quite different expectations based on their experiences, attitudes and values. It is essential for you to be clear about the expectations the consumer has of the possible process and outcome of their case, so that they remain in control. This requires listening well, asking questions, conveying the rights of the consumer in relation to the case and discussing what you might know of the reality of the outcome

of the advocacy actions. Some consumers might have quite unrealistic expectations of the outcome, some might underestimate the seriousness of their situation and the steps needed to arrive at an outcome. Some consumers might have a real fear of challenging authority and finding themselves in a position of conflict. These expectations need to be discussed thoroughly.

It is often easy to make promises in relation to the progress and outcome of the case. Not only are you not in a position to predict the outcome of a case, even though you might try your hardest for the most positive and advantageous outcome for the person you are assisting, broken promises or promises that you are not able to deliver on, reduce the trust and fracture the relationship with the person you are assisting. It is, therefore, crucial to:

- Promise only what you can deliver
- Honour any promises that you do make or indicate as early as you can that you are unable to meet the promise.

Attitudes, values, humility, modesty and ethical conduct overlap - they are all essential qualities for becoming an effective community support advocate. The next indispensable criterion is establishing authority to undertake advocacy.

d) Community Support Advocacy and Authority

There are two aspects to the concept of 'authority' in relation to community support advocacy:

- The first is to identify the extent of *personal authority* and to establish *authority to act* as an advocate in support of and/or on behalf of another person.
- The second is to *challenge the authority* held by the individual, agency or institution against which the person you are assisting has a claim.

Personal and delegated authority

Western democratic societies confer on their citizens the right or authority over most aspects of their personal lives. This authority may also extend to their children to a certain age and, through Power of Attorney, to others they may be legally responsible for. Personal authority, however, does not extend beyond the individual and the people they are legally responsible for unless authority for someone else is entrusted to them.

Delegated authority gives the right to influence, control or direct the actions of other people. Authority can be given in law, by custom, by understood rules of morality or by consent of the person under authority.

If explicit consent, or delegated authority, is not sought and given to you when acting on behalf of the person you are assisting, you are in danger of breaching privacy and confidentiality, and jeopardising the relationship of trust you have built up with the consumer.

In many instances, the agency you are dealing with will demand to see a copy of the authorisation or consent that allows you to act on the consumer's behalf. (See a sample of a consent form at the end of this manual.)

Challenging the Authority of Individuals, Agencies and Institutions

Historically, the health system is renowned for power imbalances between the service provider and the consumer. It is a strong consumer who attempts to redress entrenched attitudes and values in a system which has only recently recognised and is making gradual changes to seeing the consumer as central to the system and addressing their needs, rather than being orientated to the needs of the organisation.

Whenever you lodge a complaint or attempt to redress an injustice, you are most often challenging the power relationships and the norms of accepted conduct of an individual, agency or institutionalised system.

We are all, to some extent, raised to respect and co-operate with legitimate authority. To question it is something that those holding authority do not usually encourage.

To many this may be a very daunting prospect; to others it presents a challenge with the potential for real change. To challenge the system takes skill, courage, and preparation, knowing your rights and being clear on your authority or right to have your case heard and acted on. To be otherwise might result in consciously, or unconsciously, avoiding situations which may be perceived to result in conflict, consequently reducing the effectiveness of the outcome and the needs and interests of the person you are helping being compromised.

(Kendrick, M. *'Advocacy and the Challenging of Authority'*. 2000)

6. The Process of Community Support Advocacy

Underlying the process of community support advocacy is a belief in the consumer and their experience within the health system, establishing consent to assist and/or advocate on their behalf and understanding the limits of your participation. The process of advocacy consists of listening, securing authority, acting, consulting and conferring.

Advocacy actions are those activities that go towards:

- moving the matter that you are dealing with forward
- providing an opportunity to make it known to others that you are involved in the matter and there is an independent party assisting the person in need
- demonstrating to the person you are assisting that you see their needs are real and you are prepared to stand beside them, or that you will honestly indicate when you cannot do this.

These are the essential steps in advocacy:

- listen
- agree on next action
- establish authority
- take agreed action
- confer on each step
- push harder if necessary
- let go if necessary

Listen

1. The first step is to hear the whole story.
 - people know what they need to say and tell their story without interruption.
 - a natural reaction is to take some degree of control by asking questions and show that you are listening.
 - understand that whatever information people choose to tell is important to them even if the significance of the details may not be clear to you.
 - never make a judgment on only one part of the story.
2. Resist interrupting and the temptation to lead the conversation.
 - As soon as you interrupt, you start to influence the flow of the story the consumer is telling you.
 - Be aware that your questions reflect your focus, your values and the things you see as important and may take the consumer away from what they were wanting to say.
3. Resist feeling overwhelmed by the detail.
 - A lot of information may not feel like useful facts.
 - Try to see the bigger picture and develop clarity of the situation.

Agree on the Next Action

- It is vital that the decision about what to do next is well discussed and explores all possibilities. Your ability to explore options creatively and collaborate is important in building trust and a partnership.
- Always take your lead on the next advocacy step from the person you are assisting. Sometimes it is easy to jump to a conclusion about a strategy that may be based on limited information. Often a situation is more complex than it first appears.
- Before taking any action, it is essential to consider any unintended consequences of your planned activity. To do this, you must 'step back' from the action and consider any other party around the issue or the consumer who may be affected by what is proposed. This may require seeking permission from those who may be affected, or alerting others to the possible consequences. This most often applies to involvement with media, where others' privacy or standing may be affected.
- As a District Health Advisory Council member you have certain obligations to your DHAC, the Chairperson and the Health Service. If in doubt about these obligations you should check with the DHAC Chairperson taking care not to breach individual confidentiality.
- Remember that you can only agree to an action that you feel comfortable taking and have the capacity and skills to carry out. You must also only agree to an action that is reasonable and well justified. If you have a sense that what is being asked of you feels 'not quite right' you could perhaps consult with an experienced advocate (eg. from the Health Consumers' Council) or express your concerns and discuss them openly.

Establish authority (consent) to proceed

The person that you are assisting must give you explicit consent to speak to others on their behalf. This is vital to opening up any discussion with other people you may need to speak to. This consent is best given in written form (see an example of a simple consent form that you can use at the back of

this manual). A written consent statement can cover a number of parties and can be as broad or as narrow as you like.

Consent can also be given verbally by phone from the person you are helping, to the agency you may be approaching.

If you approach an agency or individual and they openly speak with you without the permission of the person you are assisting, you are engaging in a breach of privacy or confidentiality. You must protect yourself and the person you are assisting by having their explicit authority to speak with others.

Taking the agreed action - 'Advocacy Actions'

You enter the role of an advocate when you speak for another, seek to exercise influence and work for an outcome. This is the challenging part of acting in the role of an advocate because you are entering an unknown territory that may include some degree of conflict or tension. Most of us avoid conflict situations, so taking each advocacy action can lead to nervousness and anxiety about your performance. These reactions are normal, and practice makes the process less daunting.

Advocacy actions can be any step you and the person you are helping can think of, but usually include:

- Arranging a meeting to discuss issues
- Attending an appointment or meeting already planned
- Sending a fax or email seeking a quick turnaround response
- Sending a letter for a more formal approach
- Making a phone call seeking information
- Researching options available
- Negotiating an outcome

One of your first ports of call may be the hospital or agency against which the person you are assisting has a grievance. Some public hospitals have a Complaints Officer or Consumer/Customer/Patient Liaison Officer whose

job is to deal with complaints. If the agency or hospital does not have such an officer, the Director of Nursing, District Manager, Regional Director or Chief Executive Officer is the person to contact.

Confer on each step

It is good advocacy practice to return to the person you are assisting as soon as possible after each step to discuss what has occurred, especially if that person is not present at meetings. There are a number of reasons for this:

- Accountability. Reporting back to the person you are assisting is respectful. You should never say anything to others which you would not say to the person you are assisting
- Reduces the risk of compounding misunderstandings
- The information you gained from one advocacy action may change the course of the next planned step. Only the person you are assisting has experienced the reason for their need for advocacy and can see new information in its full context and what it may mean to them.

Push harder if necessary

This step deals with the need to 'escalate pressure' or push harder if there appears to be good reason to do so.

If you start the advocacy process aggressively, it is difficult to then push harder because all that is left is more aggression. Starting the advocacy process at a steady, calm, reasonable level is the best basis for later increases in pressure if this is needed. This means that letters, conversations, meetings and processes are all low-intensity and even-handed, generally seeking to lay out concerns without inflammatory statements or claims. The fact that an advocate is involved is usually enough implied pressure at an early stage.

If, as a result of the first information gathering stage, you see a fair case for extra pressure, you must be prepared to go to that next step. If you pull

back from a just cause, you can do more harm than good. However, there are times when it is necessary to let go.

Let go if necessary

There are several reasons for just letting go of an advocacy effort. These include:

- The person you are helping no longer needs assistance
- You find information that seems to diminish the case to the point you feel unable to continue
- There is no further help you can offer at this time, although the person may still work on the issue on his or her own account
- The scale of need is beyond what you can offer

7. Tips for Improving Advocacy Skills.

Perhaps the two most important skills used in advocacy are listening skills and dealing with conflict. As you have noticed in the preceding section, listening carefully to what the person is telling you so that you can get a thorough understanding of their view of the problem is critical. Moreover, because advocacy actions entail challenging authority which can often bring some degree of conflict, so the skills required to handle conflict with the least amount of harm to you, the person you are assisting and the advocacy case, are also important.

a) Listening Skills (from <http://www.infoplease.com>)

Active and careful listening to the person you are assisting is the starting point for any form of advocacy. It is also an essential component of discussions with the agencies you are dealing with. Here are some tips to improve your listening skills:

- Give your **full attention** to the person who is speaking and **act** like a listener. Use your body language and facial expressions to show that you are not only listening but also are interested in what the other person has to say. Observe the person's body language. Bear in mind that only 30% of communication is verbal, which leaves 70% of communication expressed in body language such as facial expressions,

hand gestures, posture and so on. Get as much information as you possibly can from both forms of communication.

- **Concentrate** on what the person is saying. Don't assume that you know what the speaker is going to say next. Keep an open mind and do not make any judgments until you have heard all that is to be said. Remember that it is your job to try to understand the attitudes and values of your speaker. Their attitudes, values, experiences and cultural perspectives form your speaker's ideas and the way they present information.
- Never **interrupt** the speaker. Wait until the speaker has finished before asking follow-up questions, making comments or confirming what the speaker has said.
- Give **feedback**. It might be unconsciously given in the form of body language (nodding your head) or through phrases such as *I see*, *OK*, etc which do not interrupt what the speaker is saying, but confirms that you are listening. When the speaker has finished, **repeat** back what you think they have said in your own words.
- Ask **questions**. Don't assume that you fully understand everything the speaker has said. If you feel as though you might have missed the point, ask for clarification.
- Take **notes**, or use a tape-recorder with the other person's permission, to make sure that you remember all that has been said. After studying your notes and analysing what was said at the meeting, return to the speaker and confirm that you have the same understanding of the situation.

b) Dealing with Conflict

The aim of advocacy - to redress injustice and reclaim rights - most often involves confrontation and conflict. This is to be expected when individuals and agencies are placed in a situation in which their conduct, performance and authority are questioned. However, conflict does not always need to be negative or destructive. Conflict is sometimes referred to as `creative

tension' that has the effect of focussing the attention of the people involved and encouraging problem solving.

- Most people are raised to respect and defer to authority. To challenge this may lead you to doubt your right and ability to question authority and you may be reluctant to do so. However, without challenging authority, you will not be able to advocate effectively. Be aware of **your right** to challenge authority and remind yourself of the reasons for doing so.
- Take each step one at a time. Be **fully prepared** before going into meetings by knowing as much of the situation as possible, doing additional research if needed and knowing your rights and the rights of the person you are assisting. Be prepared to slow the process if time will enable you to be better prepared.
- Keep your **cool**. It is pointless and unproductive to be volatile even though you may be placed in a situation that you find untenable.
- Take time to **debrief** (talk over the issue, problem or situation) after a session in which you may have been subjected to conflict. Remember though that the advocacy case and its details must remain confidential. This may be difficult in a small town where everyone knows everyone else. If you are in this situation, you might wish to contact an advocate at the Health Consumers' Council. Health Consumer Council advocates have strong shoulders, willing ears and lots of good advice based on years of experience.
- Remember that the **courage** and confidence needed to deal with conflict is a learned condition. The more you practise advocacy, the better you will become at dealing with conflict and confrontation.

8. Boundaries of Community Support Advocacy

Advocacy situations that appear to be straightforward can actually become quite complex. Other seemingly complex situations can be resolved surprisingly quickly. An advocate must always be open to developments in

the situation they are assisting with that demand a different approach or help from others with particular expertise. The challenge is knowing when you are coming to the limit of what your skills and knowledge enable you to do. The best warnings about reaching a limit in advocacy work generally come from intuition or an inner sense that the next step is so unclear as to justify stopping until a clear path emerges. This may require research to obtain the information you need to decide on a next step, or it may require passing the task on to a more qualified person.

a) When to Call In or Call On the Experts

There will always be people with expert knowledge in our community on any topic and these people will usually share their knowledge fairly readily.

Finding the right information from the right person is generally a process of identifying the nearest likely expert and then working from there. If the person you ask first does not have the answer, they are likely to be able to suggest another source for you to approach, and in this way, your knowledge will build.

This activity of progressive research to find out more information may also bring you into contact with people or agencies that can step into your place as advocate and take on the role of assisting the person in need. You may then take a supportive role in the background or step aside altogether.

An example could be a complaint about rudeness revealing a strong discriminatory practice that needs to be dealt with by a stronger process than simply a complaint. This may result in the person taking the matter to the Equal Opportunity Commission, which sets in train a very formal process. Your role may then be as support person through that process.

b) Legal Issues

Legal knowledge and practice is so specific that no one other than qualified lawyers or paralegals should ever give legal advice. The problem for non-legal people comes in knowing whether there is a legal dimension to a complaint or situation that you may be assisting with. It is important to not

venture into speculating about legal matters or expressing an opinion based on little knowledge. This is especially important because your opinion may be given extra weight because you have assumed an advocacy role. Raising false hopes about legal options and redress can be very harmful to the relationship that you have with a person you are assisting.

Community legal centres, the Citizens Advice Bureau and Legal Aid are all good starting places for exploring the threshold question of whether there is a legal dimension to a situation you are assisting with. It is then a matter of researching the best source of legal advice and the most affordable option for the person concerned. It is also necessary to consider that the person may not want to pursue their legal rights even if this avenue is available and as such, this needs to be respected.

Of course, if you are unsure of who to contact first or whether the case has a legal dimension, your first port of call should be the Health Consumers' Council who can give immediate advice.



CONTACT

HEALTH CONSUMERS' COUNCIL



9. Assisting People from Minority Groups

Although all people requiring assistance with advocacy cases should be treated as individuals with their own attitudes, values and ways of doing things, there are groups of people within society who may require additional thought and sensitivity.

a) Mental Health Consumers

Mental health consumers are, like other health consumers, faced with problems within the health system. However, the stigma associated with mental illness and its effects, can have consequences on the way in which they are treated by society and by the agencies with which you are dealing. It is important to remember that:

- Most often the situations which mental health consumers experience and their stories are not believed. Always presume the credibility of their story unless proved otherwise.
- Always assume the competence of mental health consumers unless it is proved otherwise.

Here are some very useful ideas to help understand and communicate with a person with a mental illness.

How to communicate with a person who has a mental illness

by Roy Dobson, NMAHS Mental Health.

Some people suffer from complex mental disorders that distort the way they think, feel and behave. Their ability to interpret information and their perception of others may also be distorted.

Remember that what a person says and feels or their behaviour toward you is not a personal attack but it could be a consequence or belief of their mental state. Do not take it personally or aggravate the situation by contributing to it in a defensive or hostile manner.

Do not treat someone according to their label or what you think is wrong with them. The label is not the issue.

Accept the person for who they are. Be genuine and establish trust and rapport with that person.

Do not be judgmental but be accepting of the person.

Treat the person how you would like to be treated, or how you would treat anyone else.

Listen to what the person is saying and try to understand where he/she is coming from. Recognise and acknowledge his/her feelings. You do not have to solve problems only be there for the person.

Some people have confusing or conflicting beliefs about 'good' and 'evil', 'God' and the 'devil' and they may be in constant struggle in their minds about the two. Religious struggles may be part of their delusions. They may blame others for their illness or may have lost all faith and hope in their situation. Some people may want to build hope and seek religious beliefs, while others may feel let down by the faith they believed in and wonder why they have to suffer constantly. Some people ask, 'Am I not worthy of happiness and acceptance? What have I done wrong? Is my God a loving God? If so, why am I suffering?' Listen to the person and let him/her ventilate their feelings, frustration or anger. Do not argue or provoke an altercation. Most of the time people want to be listened to and want someone to understand their constant conflicts in a non-judgmental way.

Some people may have problems understanding what is said, because their minds are flooded with thoughts that they are unable to process readily. Their speech may sound confused and disjointed, incoherent or even bizarre.

Do not display fear or intimidation when the person displays anger or frustration. Allow him/her to express his/her feelings and frustration. Listen to the person. There is no need to say anything. Be mindful of your body language and maintain attentive eye contact.

Do not argue and don't agree with what the person is saying if you know that what he/she is saying is wrong or untrue. Instead, listen. Acknowledge that what he/she is feeling or thinking may be real to them but not to you. Try to base the conversation on what is really happening.

Listen and show empathy. Communicate in simple, honest and clear terms. Some people may get confused with jargon terms and may misinterpret what you are trying to tell them.

Give body space between yourself and the person you are talking to. Some people cannot handle the closeness or the touch of another person, no matter how good the intention is.

Assess the situation by observing body language, verbal content and tone of the conversation. If the person is getting uptight or upset, allow some distance between the person and yourself. Offer to discuss this conversation at another time.

There are some people who would take a lot of someone's time and the listener may feel 'exhausted' or 'drained' from listening attentively and trying to digest the information. Protect yourself from 'burnout' by setting time limits with the person. Arrange another time or day to talk about things.

It is important that you terminate the interview calmly and without 'half-solved' issues. It is okay to say I don't know, or I can't do this and refer on if needed.

This list is not exhaustive but is basic communication with someone with mental illness.

b) Consumers from Aboriginal Communities

It is most probable that you may be called on to assist a person from an Aboriginal community in redressing injustices. You are strongly advised to contact the Aboriginal Liaison and Advocacy Officer at the Health Consumers' Council for advice.

The Health Consumers' Council want to make their work more accessible to Aboriginal people and so have employed two Aboriginal workers- Brian Charlie and Laura Elkin- to extend the council's work to Aboriginal people all across WA. Funding for the project has been provided by the Office for Aboriginal and Torres Strait Islander Health for a three year period.

Laura's role is to recruit and provide training for Aboriginal people interested in becoming consumer representatives. This engages consumers in decision-making processes about their own health care, health service planning, policy and delivery. Consumer input can also achieve better health outcomes with improved communication and better identification of the needs of those using a service.

The Health Consumers' Council have been training consumer representatives since 1996. We currently have 48 consumer reps on 132 committees, covering a wide range of health issues locally, state wide and nationally. Laura can run workshops in your community and will continue to provide support. We want to empower more Aboriginal people in consumer representative roles on committees and other decision-making forums. This is essential if we want to see changes in health organisations that truly reflect the needs of Aboriginal people.

In addition, the complaints review component of the project will work in partnership with Community Controlled Aboriginal Health Services to review and improve health complaint processes for Aboriginal people. This will be done by Brian Charlie.

As well, Brian's role is to consult with Aboriginal health consumers on their experience of using health services (public, private and community controlled) and improvements that might be made through more responsive complaints processes.

c) Consumers from Ethnic Minority Groups

Along with the issues that all consumers face in the health system, people from culturally and linguistically diverse backgrounds experience several more barriers: language and cultural differences and the lack of knowledge of the way the health system works in Western Australia.

- *Language barriers:* Although most people arriving from other countries make learning English a top priority, in times of stress such as illness, an unjust situation or the confrontation of advocacy, the second language is usually dropped and the person reverts to their first language. Assisting them in running an advocacy case may be a stressful situation requiring the use of interpreters to help with communication.

The Telephone Interpreter Service (TIS phone number – **13 1450**) provides interpreters immediately via the phone or you could book a face-to-face interpreter for interviews and meetings although these may be costly. The advantages of using an interpreter, apart from having an easier and more effective channel of communication, is that an interpreter is qualified and has the range of vocabulary needed in both languages to deal with most situations. As well, an interpreter is bound by a code of ethics to keep all information confidential.

- *Different cultural perspectives:* Attitudes and values can vary widely between cultural groups. In some cultures, medical staff might be accorded a status that discourages questioning their authority. In other cultures, it is becoming increasingly common to query medical judgments. People from other cultural groups may also see the causes of illness and how these should be treated quite differently to how disease is explained in Australia. To understand cultural differences, it is necessary to **ask** the person you are assisting what their

understanding of the problem or situation is and try to accommodate their explanation – even if it seems odd or incomprehensible to you.

- *Lack of knowledge of the health system and other Australian institutions:* As with many Australians, the health system and the rights of health consumers are most likely to be very foreign to people from immigrant groups. Very few health systems in the world are alike. It can be very confusing for someone who is familiar with one health system to have to deal with a totally different system and its components without prior knowledge of what to expect or how it operates. An initial part of the advocacy process can be to simply explain (if possible) the Australian health system and to locate the complaint within it.



10. Sample Forms

Example consent form

Statement of Authority

I,-----, *(person needing help)*
give my authority for -----*(person acting as an*
advocate) to discuss with -----*(individual*
or agency)
matters relating to my current health complaint.

Signed: ----- Date: -----

Sample letter requesting access to information.

8 Jones Street
Smithtown WA 6222

FOI Coordinator
District Hospital
Locked Bag 3
Smithtown WA 6222

Dear FOI Coordinator

I seek copies of my records throughout 2002. My date of birth is 29 October 1955 and I can be contacted on 9333 4444 for further information that will assist you in responding to this request.

Yours sincerely

Sarah Jane Clark
31 October 2006

Sample Fax letter

Unit 13/14 Wellington Fair
40 Lord Street
EAST PERTH WA 6004

GPO BOX C134
PERTH WA 6839

Telephone: (08) 9221 3422
1800 620 780

Facsimile: (08) 9221 5435

FACSIMILE TRANSMISSION



Pages Transmitted: 2

Date: 6 Jan 06

TO:	Dr Carter
FAX NO:	9258 8442
SUBJECT:	Tom C
FROM:	Maxine Drake - Advocate

MESSAGE:

Dear Dr Carter

The Health Consumers' Council is an independent community based organisation representing the consumer's 'voice' on health policy, research and service delivery. The Council provides an advocacy service to individuals experiencing problems in the health system. Tom's mother Debra has been in contact with this office since early November 05, after it was identified that a piece of brace wire was lodged somewhere in Tom's mouth. Debra has had discussions with us at each point since then to clarify her rights and obligations in respect to dealing with this unintended outcome of the orthodontic treatment you provided to Tom.

I understand that the appointment on Monday 9 January will be a final step in the orthodontic treatment process and also that you will assess Tom's wisdom teeth and determine a time frame for their removal. We understand that a specialist has indicated that he is prepared to perform the wisdom teeth removal and at the same time deal with the removal of the retained piece of brace wire. It is fortuitous that both matters can be dealt with at the same time.

It is recognised that the retention of the brace wire in Tom's mouth was unintended and has required Tom to attend for more assessment and treatment than would otherwise have been needed. We ask on behalf of Tom's mother that you consider the extent of your liability for the out-of-pocket costs associated with

this additional involvement and what percentage of these you would be prepared to meet. It is gratifying that the specialist has indicated that he will provide his services for no fee additional to the available rebate. We understand that the costs faced by Debra to date are in the order of \$120.00 for the gap on the cost of the x-rays needed to determine whether the wire was retained in Tom's cheek or gums.

This matter could be addressed at the appointment on Monday, or deferred to a meeting for that purpose.

Thank you for considering the matters raised. I have been asked by Debra to attend the appointment on Monday in my capacity as Advocate. I hope that this fax provides as opportunity for the issues to be considered before the appointment and resolved there if possible.

Regards

Maxine Drake

11. Definitions

Advocacy	Support or argument for a cause, policy, etc
Advocate	A person who supports or speaks in favour of someone or something. A person who pleads for another.
Authority	Delegated power. An influence exerted on opinion because of recognised knowledge or expertise.
Ethical	Relating to morals, especially concerning human conduct: morally, correct, honourable.
Promise	An assurance that one will or will not undertake a certain action, behaviour, etc.
Systems advocacy	Those activities directed specifically towards the systems, structures and forms that are instrumental in the conditions that create injustices and inequities.

12 Resources: – Where to go for help.

Organisations

The following information has been taken from the websites of each organisation.

Health Consumers' Council WA (HCC)

The Health Consumers' Council is an independent community based organisation, representing the consumers' 'voice' in health policy, planning, research and service delivery.

The Council advocates on behalf of consumers to government, doctors, other health professionals, hospitals and the wider health system.

The Council has 5 clear objectives:

- 1) Helping you understand health issues.
- 2) Encouraging your participation in decisions that affect the health system.
- 3) Encouraging accountability in the health system to ensure that our money is spent wisely and productively.
- 4) Giving people who use the health system access to advocacy, information, training and support.
- 5) Helping our community understand the health system.

Contact details (8.00am-5.00pm, weekdays except public holidays)

Telephone: (08) 9221 3422

Freecall: 1800 620 780

Facsimile: (08) 9221 5356

Email: info@hconc.org.au

Website: www.hcc-wa.global.net.au

Office address: Unit 13/14 Wellington Fair 40 Lord St, East Perth
WA 6004

Postal address: GPO Box C134 Perth WA 6839

Carers WA

Carers WA is a non-profit community based organisation and registered charity dedicated to improving the lives of family Carers living in Western Australia. Part of the National Carers Association, Carers WA is the peak body recognised both state and federally, as the voice of family Carers, representing carers interests in the Western Australian community.

The role of Carers WA is to work in active partnership with Carers, persons with care and support needs, health professionals, service providers, government and the wider community to achieve an improved quality of life for Carers.

Carers WA provide information and resources, counselling, social support, education and training and assisting special needs groups such as young carers, mental health carers and carers from culturally and linguistically diverse backgrounds.

Contact details

Telephone: (08) 9444 5922

24hr Carer Counselling Line: 1800 007 332

Commonwealth Carer Resource Centre: 1800 242 636

Facsimile: (08) 9444 8966

Email: info@carerswa.asn.au

Website: www.carerswa.asn.au

Office address: 255 Walcott Street North Perth WA 6006

Citizens Advice Bureau/Mediation Service WA (CAB)

The CAB located throughout WA provides an informal dispute resolution service to all sections of the community. The CAB provides a free confidential, impartial information and referral service to any person or organisation, and offer free assistance from a variety of experts including Justices of the Peace, Tax Help and assistance with simple Probate

applications. The CAB provides a legal advice service in family law matters, consumer queries, debt, criminal, and personal injury matters.

Contact details

Phone number: (08) 9221 5711

Facsimile: (08) 9221 5356

Email: cab@cabwa.net.au

Website: www.cabwa.com.au

Address: 25 Barrack St Perth WA 6000

The Equal Opportunities Commission (EOC)

The Equal Opportunity Commission has two major roles. The first is to encourage recognition and an understanding of the principles of equal opportunity. Laws alone do not end intolerance, prejudice and discrimination in our community - so education is a vital part of the Commission's function.

The second is to provide a means of redress to individuals who allege unlawful discrimination. Since the Equal Opportunity Act was proclaimed in 1985, the Equal Opportunity Commission has received more than 60,000 enquiries and handled 4,500 complaints.

Contact details (9am – 4pm weekdays)

Telephone: (08) 9216 3900

Freecall: 1800 198 149

TTY: (08) 9216 3936

Facsimile: (08) 9216 3960

Website: www.equalopportunity.wa.gov.au

Address: Level 2 141 St George's Terrace Perth WA 6000

Freedom of Information: Information Commissioner (FOI)

The *Western Australian Freedom of Information Act 1992* (the *FOI Act*) gives you the right to apply for access to documents held by State Public Sector agencies which includes: Government Departments; Local Authorities; Statutory Authorities and Ministers.

Agencies are required to assist the public to obtain access to documents at the lowest reasonable cost, and to ensure that personal information held is accurate, complete, up to date and not misleading. Your right to apply is not affected by any reasons you have for wishing to obtain access, or the agency's belief as to what your reasons are for applying.

The kinds of documents to which you may request access includes paper files, computer records, maps, plans, photographs, tape recordings, films, video tapes and electronically stored information.

You may also apply for access to personal information about you that is contained in agency documents and you can correct that information if it is incorrect, inaccurate, out of date, or misleading. Personal information is information about you whilst non-personal information is information concerning other people.

The FOI Information Commissioner is an independent officer whose main function is to deal with complaints made about decisions by agencies in respect of access applications and applications to amend personal information.

Other responsibilities of the Information Commissioner include:

- ensuring that agencies are aware of their responsibilities under the *FOI Act*.
- ensuring that members of the public are aware of the *FOI Act* and their rights.

- providing assistance to members of the public and agencies on matters relevant to the *FOI Act*.
- recommending to Parliament legislative or administrative changes that could be made to help the objects of the *FOI Act* be achieved.

Contact details

Telephone: (08) 9220 7888

Freecall: 1800 621 244

Facsimile: (08) 9325 2152

Email: info@foi.wa.gov.au

Website: www.foi.wa.gov.au/About.htm

Office Address: 12th Floor, St Martin's Tower
44 St George's Terrace Perth

Postal Address: PO Box Z5386
St George's Terrace Perth WA 6831

Legal Aid Western Australia

Legal Aid Western Australia is an independent statutory body set up by the *Legal Aid Commission Act 1976*. Legal Aid Western Australia provides information, advice and other legal help and aims to provide services for people who are disadvantaged in accessing legal help. The type and amount of help depends on the consumer's financial situation, the legal problem and Legal Aid's resources.

The services provided include:

- *Information services*: through the telephone information line, community legal education, the website and a range of publications and kits.
- *Legal advice*: through the duty lawyers at court or legal advice sessions, either face to face, over the telephone or by video conference to people in remote areas.
- *Minor assistance*: through solicitors or paralegal advisors who can help negotiate, write letters, draft documents or prepare to represent yourself in court.

- *Legal representation*: through lawyers working for Legal Aid as well as private lawyers. Only people with incomes and assets below a certain level get their own lawyer.

Specialist services are provided through:

- * Child Support Legal Unit
- * Domestic Violence Legal Unit
- * Immigration Service
- * Youth Law Unit
- * Alternative Dispute Resolution Unit
- * Corruption and Crime Commission Representation Fund

Contact details

Telephone: 1300 650 579

Regional offices: Fremantle 9335 7108
 Midland 9274 3327
 Great Southern 9892 9700
 Kimberley 9195 5888
 Southwest 9721 2277
 Goldfields 9091 3255
 Pilbara 9172 3733
 Midwest & Gascoyne 9921 0200
 Christmas/Cocos Islands 9164 7529

TTY: 1800 241 216

Office address: Ring the phone number to find the address of the nearest Legal Aid office.

Website: www.legalaid.wa.gov.au

Office of Health Review

The Office of Health Review is an independent State Government agency established to deal with complaints about health and disability services. We provide a free service to all users of health and disability services in Western Australia.

The Office of Health Review was established in 1996 to deal with health complaints under the *Health Services (Conciliation and Review) Act 1995*. Our role was expanded in 1999 to include enquiries into complaints about disability services. These complaints are dealt with under Part 6 of the *Disability Services Act 1993*.

The Office has the power to deal with health and disability complaints. The majority are handled through the conciliation process. We also have formal powers of investigation. These include: the power to issue a notice for the production of information and also require the attendance of a person to answer questions under oath or affirmation. The Director can also prepare a report for Parliament on any matter arising from a complaint or any of the functions for the Director. The Director has the power to make recommendations following an investigation, however, there is no power to enforce compliance with these recommendations.

Contact details

Telephone: (08) 9323 0600

Freecall: 1800 813 583

Facsimile: (08) 9221 3675

Website: www.healthreview.wa.gov.au

Office address: Level 12 St Martin's Tower
44 St Georges Terrace Perth WA

Postal address: GPO Box B61 Perth WA 6838

Office of the Public Advocate (OPA)

In Western Australia the Public Advocate is the independent statutory officer appointed under the *Guardianship and Administration Act 1990* to promote and protect the rights, dignity and autonomy of people with decision-making disabilities and to reduce their risk of neglect, exploitation and abuse.

The Public Advocate assists in protecting the rights of people who are not able to make reasoned decisions because of dementia, intellectual disability, mental illness or acquired brain injury.

The Public Advocate provides the following services:

- * information, advice and training on how to protect the rights of people with decision-making disabilities;
- * investigation of concerns about the well-being of a person with a disability and whether an administrator or guardian is required;
- * investigation of specific applications made to the State Administrative Tribunal to assist the Tribunal to determine whether a guardian or administrator is required; and
- * guardianship services (for medical and lifestyle related decisions) when the State Administrative Tribunal determines that there is no one else suitable or willing to act as the person's guardian.

The Public Advocate provides a statewide Telephone Advisory Service (TAS) for people who have a personal or professional interest in the rights and needs of people with decision-making disabilities. Guardians and investigators provide the service, which operates during normal office hours.

Contact details

Telephone: (08) 9278 7300

Freecall: 1800 807 437

Facsimile: (08) 9278 7333

Email: opa@justice.wa.gov.au

Website: www.justice.wa.gov.au

Enduring Power of Attorney information line: (08) 9278 7301

Office Address: Level 1, 30 Terrace Road, East Perth WA 6004

Postal address: Office of the Public Advocate, PO Box 6293, East Perth WA 6892

State Administrative Tribunal (SAT)

The **State Administrative Tribunal (SAT)** in Western Australia deals with a broad range of administrative, commercial and personal matters. These matters span human rights, vocational regulation, commercial and civil disputes, and development and resources issues.

The Tribunal is the primary place for the review of decisions made by Government agencies, public officials and local governments. It also makes a wide variety of original decisions.

Given its broad jurisdiction, SAT matters are divided into four streams that enable procedures to be adapted to suit the type of matter and the needs of different people who use the SAT. The streams are:

- *Human Rights* : Makes decisions that affect some of the most vulnerable people in our community in relation to guardianship, administration and discrimination, and reviews decisions of the Mental Health Review Board.
- *Development & Resources*: Reviews decisions made by Government regarding planning, development and resources, and hears matters relating to land valuation and compensation.
- *Vocational Regulation* : Hears complaints concerning occupational misconduct and reviews decisions concerning licensing.
- *Commercial & Civil*: Deals with strata title and retirement village disputes, commercial tenancy and credit and reviews State revenue decisions and other commercial and personal matters.

Contact details

Telephone: (08) 9219 3111

Freecall: 1300 306 017

Facsimile: (08) 9325 5099

Website: www.sat.justice.wa.gov.au

Office Address: State Administrative Tribunal,
Level 4, 12 St Georges Terrace,
Perth WA 6000

Postal address: GPO Box U1991, Perth WA 6845

Western Australian Council of Social Services (WACOSS)

Since 1956, WACOSS has been developing and strengthening the non-government community services sector's capacity to assist all Western Australians.

At the heart of its activities, lies the belief that the mark of a civilised community is the support and help it gives to those most in need.

WACOSS and its members aim to improve the quality of life of people disadvantaged by the inequities of our society through:

- * Improving community services by exchanging ideas, information, skills and resources
- * Creating a strong, united and informed voice capable of advocating for the social needs of all Western Australians

A continual consultation process with members, their clients, the general public and other professional organisations enables WACOSS to identify and address social inequities within the community.

WACOSS also provides government with feedback on policies and programs to ensure they are relevant, and offers an alternative avenue through which government can discuss sector issues with service providers and consumers. It further advocates the views of the sector by providing information and comment to the media and the public through media releases, regular newsletters and by making representatives available to speak at public forums. WACOSS is part of an extensive network comprising Councils of Social Services in all Australian States and Territories and a national body (ACOSS), based in Sydney.

Contact details

Telephone: (08) 9420 7222
Freecall: 1300 658 816
Facsimile: (08) 9486 7966
Email: info@wacoss.org.au
Website: www.wacoss.org.au
Office address: City West Lotteries House
2 Delhi Street, West Perth, WA 6005
Postal address: as above

The Western Institute of Self Help (WISH)

The Western Institute of Self Help is a not-for-profit organisation that was established to provide support and assistance for individuals and self-help support groups in starting up, ongoing development, advocacy and networking.

WISH promotes the philosophy and practice of self-help throughout Western Australia. Fostering empowerment among self help and support groups allows people dealing with stressful like problems and situations to share their experiences and to offer emotional and practical support to one another.

Contact details (9 am – 4 pm, weekdays)

Telephone: (08) 92284488
Freecall: 1800 195 575
Facsimile: (08) 9228 4490
Email: info@wish.org.au
Website: www.wish.org.au
Office address: 335 – 337 Pier St, Perth (opposite Perth Oval)
Postal Address: PO Box 8140, Perth Business Centre, WA 6849

Publications

Kendrick, Michael (2000), 'Advocacy and the Challenging of Authority',
Citizen Advocacy Forum.

Kendrick, Michael J. (2001) 'An Ethic of Modesty In The Support Of Others', in Patricia Frantangelo, Margorie Olney and Sue Lehr, *One Person At A Time*, Training Resource Network Inc., St Augustine, FL 2001.

Parson, Ian (1994) *Oliver Twist Has Asked For More: the politics and practice of getting justice for people with disabilities*. Villamanta Publishing Service, Geelong.

(2004) *The Western Australian Public Patients Hospital Charter*, Department of Health, Western Australia.