

# Queensland Advocacy Inc.

# What is Advocacy?

There are many definitions of advocacy and much debate exists regarding which one is the most appropriate to use. Having a definition of advocacy is necessary so that we have something to refer to, to check against and to encourage discussion about what we are doing. Action for Advocacy Development uses the following definition, which is based on the work of Dr Wolf Wolfensberger. Advocacy groups in Australia discussed this definition during a National Advocacy Workshop in Sydney in June 1994. Most of these elements were agreed to:

Advocacy is speaking acting, writing with minimal conflict of interest on behalf of the sincerely perceived interests of a disadvantaged person or group to promote, protect and defend their welfare and justice by

- being on their side and no-one else's
- being primarily concerned with their fundamental needs
- remaining loyal and accountable to them in a way which is emphatic and vigorous and which is, or is likely to be, costly to the advocate or advocacy group

# Types of Advocacy

A number of different types of advocacy exist. The strength of each advocacy type depends on how well the individual, group or organisation's advocacy efforts meet the key elements expressed in the definition of advocacy. The types of advocacy have been categorised in different ways. Here we will refer to five types of advocacy:

- Individual Advocacy
- Citizen Advocacy
- Systems Advocacy
- Parent Advocacy
- Self Advocacy

Sometimes only two types of advocacy are talked about, individual and systems. Self advocacy and citizen advocacy are often regarded as individual advocacy. Parent advocacy is often regarded as either individual or systems.

# 1. Individual Advocacy

Here the advocate concentrates their efforts on one or two people only. There are two common forms of individual advocacy:

### a. Informal Advocacy

Parents, brothers and sisters, relatives, friends who take on advocacy roles are all examples of informal individual advocacy.

Many different people, with a range of relationships to people with disability, have spoken out and persistently advocated for those who are vulnerable. What often goes unrecognised and unseen, are the efforts of individual people who may struggle with the injustices with little or no support. Such individual efforts have been termed informal advocacy. These individual advocacy efforts can and do last many years, often in significant isolation.

These solo efforts can isolate individual advocates from their communities by the very nature of their efforts, particularly where the issue is controversial or perceived as detrimental to the wider system/environment in which the issue is placed. For example, a parent's efforts to seek enrolment of a child with disability in a regular school in a local community may stir enmities, conflicting interests and test established friendships.

These advocacy efforts by individual people for valued lives need to be supported, nurtured and protected. Individual people may want to be connected to others doing advocacy; to share the effort, to seek support, or to develop a collective response.

Individual advocates are encouraged to link with advocacy groups for information resources and further contacts.

### b. Voluntary community based organisations

Another form of individual advocacy is voluntary community based organisations that pay staff to advocate for individuals. In Queensland organisations that operate in this way are Speaking Up for You (SUFY), Gold Coast Advocacy Group and Independent Advocacy in the Tropics (IAT).

## 2. Citizen Advocacy

Citizen advocacy is a community based movement that aims to recognise, promote and defend the rights, well being and interests of people with intellectual and/or multiple disabilities. It does so by finding and supporting caring, responsible citizens who make long-term voluntary commitment to make a positive difference in the life of a person who may be lonely, face difficult challenges, or be in "at risk" situations.

Each Citizen Advocacy relationship is unique. The citizen advocate may for example, offer his or her protégé friendship, new experiences and opportunities, spokesmanship and protection from abuse.

The Citizen Advocacy office carefully matches protégés and citizen advocates to ensure there is a good match between the interests and needs of the protégé and the abilities, resources and commitment of the citizen advocate. Citizen advocates are orientated, assisted to gain further knowledge and resources, supported and recruited by the Citizen Advocacy office.

Organisations that operate using Citizen Advocacy are Capricorn Citizen Advocacy, South West Brisbane Citizen Advocacy and Sunshine Coast Citizen Advocacy.

# 3. Systems Advocacy

This form of advocacy is primarily concerned with influencing and changing the system (legislation, policy and practices) in ways that will benefit people with a disability as a group within society. Systems advocates will encourage changes to the law, government and service policies and community attitudes. Usually systems advocacy do not do individual advocacy. To do so can cause conflict around the use of resources, focus and purpose. Organisations that operate on a systemic level are Queensland Advocacy Inc (QAI) and Queensland Parents for People with Disability (QPPD).

# 4. Parent Advocacy

Parent advocacy is concerned with advocating on issues that affect the person with a disability and their family. The focus is on the needs of the person with a disability, not the parents or family.

However, some parent advocacy focuses on the needs of parents first. Whilst parents have substantial needs for support and resources, when we talk about parent advocacy we mean advocacy by parent groups for people with a disability.

# 5. Self Advocacy

Self advocacy is undertaken by person or group who share the same characteristics or interests on behalf of the same person or group. The difficulty with this form of advocacy is that sometimes those undertaking advocacy and speaking up for themselves are likely to be further exposed and be more vulnerable to abuse, discrimination and ridicule as a result of speaking up for themselves.

# Key elements of Advocacy

There are a number of key elements of advocacy. To briefly explain the elements of advocacy we have identified the following 6 as the predominant key elements.

# 1. Functioning by speaking out, acting or writing

Advocacy is active. It involves doing something. It may be writing letters to politicians, raising issues of concern to organisations or services, being with a person when they are confronted with situations they find difficult, being with a person where they could be taken advantage of or fighting for a person's right to live a more fulfilling life.

### 2. Minimal conflict of interest

This issue lies at the core of advocacy and is one of the hardest, most important issues to come to grips with. In any situation there will be more than one person or groups' interests that will be in conflict or competition with the interest of a person with a disability.

When you are in an advocacy role, you need to be clear as to how your interest and needs may be in conflict with the person for whom you are advocating. As an advocate you must identify and attempt to reduce conflicts of interest or, at least, be prepared to acknowledge your limitations as an advocate.

# 3. Sincerely perceived interests

This issue is one of the most complex and difficult issues for advocates to address. The advocate does not just speak up for what a person may **want** or what a person may be **interested in**. Advocates will be faced with making decisions about a person with disability's life and well being and may be the only individual in that person's life who has a positive vision for that person's future in the long term. When what a person says they want is different from what seems to be in their best interests, advocates are faced with a difficult dilemma.

Identifying what is in a person's interests, what they need versus what they want is a difficult process.

# 4. Promotion of person's welfare, well being and justice

As an advocate you do this precisely because the well being of, and justice for, disadvantaged, devalued people is often risk. Things we take for granted are often not available for people with disabilities. Devalued people are apt to be treated as sub-human with all the degrading, inhumane treatment that accompanies such notions of devalued people and people with disability in particular.

For example, people with disabilities have been placed in cages, left unattended on toilets for long periods of time, bathrooms and toilets often do not have doors fitted. Little attempt is made to ensure privacy and dignity for the person.

One must be convinced that the dynamics of oppression are a constant reality in these people's lives, so that our advocacy efforts are aimed at enhancing and protecting the value, the competencies and the image of the person for whom we are advocating, as opposed to promoting devalued social roles and images. Unless we are highly conscious and convinced of the devaluing structures and processes that operate with in the lives of devalued persons, we can actually assist and tacitly engage in, those destructive processes.

# 5. Vigour of action

Advocacy requires:

- fervour and depth of feeling in advancing the cause or interest of another
- taking a lead, initiating
- sense of urgency
- doing more than what is done routinely
- challenging the community

As an advocate you need to be prepared to bend over backwards to pursue and achieve even small, ordinary gains. Instead of only writing a letter to the editor, it may require you to also ring your local politician; instead of complaining once about an unacceptable situation, it may require you to complain weekly.

### 6. Costs

Advocacy can involve costs to the advocate and to the person needing advocacy and these costs must be considered.

To say that advocacy costs, is not to say that people with disability are costly to be with. The cost element of advocacy reflects the demands of all strong advocacy, whether for people with disability or advocacy for another purpose, for example, environmental causes. Recognising that advocacy costs, helps advocates to prepare and understand what may happen to them when they do

advocacy. People with disability need advocates who are prepared and able to be there for the long haul.

### Costs to the advocate

The potential costs to the advocate include one or many of the following at various times:

- Time or other resources that the advocate may rather spend on something or someone else such as time with your family, going to the movies.
- Emotional wear and tear that arise from the highs and lows of advocacy.
- Not being able to adequately meet bodily demands such as having time to sleep, rest, eat a leisurely dinner.
- Social rejection and ridicule that you may experience. Often by being an advocate you may suffer some of the same things devalued person or group experiences – exclusion, ridicule, rejection by your peers, work colleagues, friends.
- self esteem and self-certainty may be attached. Often people who rock the boat are labelled troublemaker, eccentric, do gooder and are treated accordingly. This may cause you to lose faith in yourself and your actions.
- Financial security and livelihood may be lessened. Your actions as an advocate may lead to the loss of promotional or job opportunities, the loss of existing job, or the cost of litigation.
- Physical health, safety and in some countries your life can be threatened as a result of strong advocacy efforts.

### Costs to person needing advocacy

When you make decisions or take actions that affect the person with the disability you need to be aware of the implications of your actions. You can achieve this by asking yourself the following questions.

- Will my advocacy efforts have the potential to cause more harm than good?
- If I do not take action how serious will be the potential outcome be?

If there is a potential cost to the person with a disability you must also warn them as to what that might be. For example, you may be advocating for a person to have visitors when they wish. Firstly, you must consider how your actions could negatively affect the person. If it is likely the person could be penalised in small ways, such as being served last at dinner, you may decide to go ahead in this situation. If the consequence could be the person being singled out by staff and made fun of in front of everyone you might decide the cost is too great. However, if you were making complaints to a service because of suspected physical and sexual abuse, the potential costs of being made fun of will almost certainly be worth stopping the abuse.

# Other key elements of Advocacy

There are other key elements of advocacy that are implied by the definition, they are:

### 1. Being on the side of the disadvantaged party

Advocacy is biased; it does not claim to be neutral. It is not about mediating, facilitating or negotiating on behalf of someone. It means placing yourself fundamentally on the side of the person with a disability. If you are advocating for – then you will be advocating against as well. There is no middle road. It does not mean you will have to be aggressive or confrontational although some situations may warrant that. It simply means clearly, consistently, and firmly acting and speaking on behalf of one person or group of people.

### 2. Fidelity / Stick-to-it-ness

Advocacy involves being there over the long run. This may involve making commitment to be in someone's life for a long time or making a commitment to see a particular situation through to its end. Some people with a disability, particularly those who are dependent on services, have little continuous contact with people. Residential care officers, mental health workers, social workers, case managers often come and go. Hence it is important to make a realistic commitment to be there.

### 3. Emphasis on major needs

As an advocate you need to concentrate on a person's fundamental needs first. A person's need for a home of their own, enduring relationships, to be free from abuse, to be healthy and safe may take priority over encouraging a person to attend personal development courses or even having work.

### 4. Mindful of parties even more needy than the person you are advocating for

There may be other parties whose needs must be considered. For example, the child of parents who lack competence is more vulnerable than those parents. Advocates for the parents must bear in mind the needs of the vulnerable child and at least arrange independent advocacy for the child.