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The nature and purposes of advocacy for people with disabilities

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THE NATURE AND PURPOSES OF ADVOCACY

FOR

PEOPLE WITH DISABILITIES

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Abstract

Although all human beings experience vulnerability, people with disabilities experience heightened vulnerability. For some people, the consequences of this heightened vulnerability may include social devaluation, physical and social rejection, a loss of control over important areas of their lives and brutalisation. Advocacy is one vital response to vulnerability and its consequences. This monograph presents the results of the National Advocacy Research Project which involved an analysis of the status of advocacy for people with disabilities within Australia and provides direction for the future development of advocacy nationally. The monograph explicates the need for and the purposes of advocacy for people with disabilities and provides an account of the fundamental principles which underpin effective advocacy. It analyses the key issues which are facing Australian advocacy efforts and finally presents a list of recommendations which relate to the future development of advocacy within Australia.

Acknowledgements

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1.0   Introduction

The National Advocacy Research Project was funded by the Commonwealth Government Department of Health, Housing, Local Government and Community Services (HHLG&CS). The project was carried out by the Centre for the Development of Human Resources, which is part of the Faculty of Health and Human Sciences of Edith Cowan University (Western Australia). Funds were provided to conduct the project over twelve months. The project began in April 1992 and was completed in March 1993.

The Project Director was Mr Errol Cocks, Director of the Centre for the Development of Human Resources. In the role of Project Director, Mr Cocks supervised the research project. The Project Coordinator was Mr Gordon Duffy, a Visiting Research Fellow who was seconded to the University from HHLG&CS. Mr Duffy conducted the research project. Funds provided by HHLG&CS were largely devoted to meeting Mr Duffy's salary and associated costs and travelling costs. Mr Cocks' contribution was provided as an additional part of his normal University duties.

The research project was considered very timely for a number of reasons.

First, the broad context of modern Western society, and of formal human services in particular, creates a turbulent environment in which personal vulnerability and risk is heightened. People with disabilities and other people who are vulnerable are faced with an environment which is changing rapidly in almost all areas of human activity and becoming less predictable. The service system is experiencing extreme pressures, even crisis, and although there are good people doing good things, the lives of many people with disabilities continue to be characterised by wounding, rejection and loneliness. Arguably, the

need for people with disabilities to have effective, independent advocates who support them has never been stronger.

Second, with most types of advocacy dating from the late 1970s and early 1980s, advocacy for people with disabilities in Australia is in a formative stage of development. During this decade or so of advocacy development, a large number of different forms of advocacy have been established in Australia. The advocacy picture is becoming increasingly complex and advocacy groups are grappling with many challenging issues. This research project may be instrumental both in providing analysis and comment on many of those issues and also in strengthening the Australian advocacy movement.

Third, there were a number of significant initiatives in 1992 which focussed on advocacy issues, a sign that the development of advocacy in Australia may be at a crossroads. They represent a heightening of interest in advocacy by governments, people with disabilities themselves and other significant groups such as service providers and professional interests. These 1992 initiatives included the following:

- A national advocacy conference was held in Brisbane in February, 1992, in conjunction with an evaluation of Queensland Advocacy Incorporated. This conference was attended by representatives from a range of advocacy organisations from all over Australia. The facilitator was Michael Kendrick, Director of the Institute for Leadership and Community Development in Massachusetts. Michael Kendrick is considered to be an international authority on advocacy for people with disabilities;

- A second advocacy research project was based and conducted within South Australia in 1992 by Judith Cross, and set out to provide South Australian advocacy efforts with clearer and greater direction. Although this advocacy project was specific to South Australian advocacy efforts, many aspects of the project could be generalised and were relevant to advocacy efforts

across Australia. As such the National Advocacy Research Project and the South Australian advocacy research project complement each other;

- In September/October 1992, Professor Wolf Wolfensberger and Susan Thomas from the Training Institute for Human Service Planning, Leadership and Change Agentry at Syracuse University and A. J. Hildebrand from One to One Citizen Advocacy, in Beaver, Pennsylvania, ran a series of training events in Adelaide, largely on advocacy. The workshop titles and a brief description of each is provided in **Appendix A.** A perusal of these illustrates a significant range and depth of issues associated with advocacy. These events attracted a large number of people interested in advocacy from across Australia. The workshops provided opportunity for consideration of crucial issues in advocacy and exposure to the ideas and teachings of Professor Wolfensberger. Professor Wolfensberger has been deeply involved with advocacy in theory and practice for over two decades and is widely acknowledged as one of the most influential of thinkers on advocacy and related matters;

- A further national advocacy research project was initiated in December 1992 and auspiced by the Disability Advisory Council of Australia (DACA).

Finally, this advocacy project should thus be seen in the context of considerable activity in the advocacy field aimed at analysing the theory and practice of advocacy and addressing a number of challenging issues associated with advocacy efforts. It is clear that these issues need much more *"airing"* and clarification. They include a range of diverse issues such as:

- the address of more fundamental, higher order issues about the nature of advocacy, particularly the moral and values base of advocacy efforts;

- threats to advocacy and the differences between advocacy and related efforts;

- an examination of why advocacy is needed and the nature of that need in modern Western society;

- issues associated with the actual development and implementation of advocacy efforts which include very practical issues such as how advocacy should be supported financially and in other ways, how and to whom advocacy efforts should be accountable, the nature and extent of the roles of governments in advocacy, and what constitutes *"good quality"* advocacy;

- the need for and nature of renewal processes to maintain the focus and energy of advocacy efforts.

The aims of this project were as follows.

1. To describe and analyse in detail the range of approaches to advocacy for people with disabilities in WA with comparative references to elsewhere in Australia and North America.

2. To develop approaches to both the evaluation of advocacy services and the training implications for the development of effective, high quality advocacy.

3. To produce a detailed report addressing a strategy for the development of effective, high quality advocacy nationally.

4. To prepare one or more proposals for the further development of advocacy services.

5. To particularly examine advocacy and related safeguarding issues in the context of the development of new service options and the transition of existing services.

6. Advise on specific features which characterise effective advocacy services.

7. Analyse the success of approaches to date, including training, in achieving consumer involvement in HHLG&CS service review processes for minimum outcomes and Section 10 reviews.

8. Advise on strategies for the development of effective consumer involvement in review processes for enhanced eligibility outcomes and in ongoing service quality issues.

This monograph, jointly written by the Project Director and Project Coordinator, is structured as a monograph to enable wide distribution and access to people with an interest in advocacy. It does not address all project aims, but focuses on the aims directly concerned with advocacy, namely, #1, #2, #3, #5 and #6. The other aims are addressed separately to this monograph.

It is important to note that this monograph has a particular focus on the broad nature and purposes of advocacy for people with disabilities and as such does not exhaustively address the myriad of specific and detailed issues associated with advocacy. There is very little material produced in Australia which provides such a broad, conceptual analysis that can serve to enhance the ongoing discourse about the future development of advocacy. Without a clear explication of the nature and purposes of advocacy, the interests of people with disabilities will not be served with full effectiveness and many issues will remain unclear and confused.

Following this introduction, the second section of the monograph describes briefly the project methodology which includes a description of some of the advocacy projects which were visited in Australia. The third section addresses the nature of advocacy and is based on a review of the relevant literature, on other information gained from discussions with people engaged in advocacy and from

training events on advocacy conducted by Professor Wolfensberger and his colleagues. The fourth section of the monograph presents an account of the fundamental principles which underpin effective advocacy, gleaned from the literature and from contact with people engaged in advocacy efforts. The monograph then provides an analysis of the critical issues associated with advocacy which are currently being faced and some which are likely in the future. Finally, a number of recommendations are detailed.

It must be acknowledged that the views and writings of Professor Wolf Wolfensberger, Michael Kendrick and their colleagues have acted as a frame of reference for a great deal of this monograph.

2.0 Methodology

2.1 Project Aims

As stated in the introduction, the aims of the advocacy project which are addressed in this monograph include the following.

1. To describe and analyse in detail the range of approaches to advocacy for people with disabilities in WA with comparative references to elsewhere in Australia and North America.

2. To develop approaches to both the evaluation of advocacy and the training implications for the development of effective, high quality advocacy.

3. To produce a detailed report addressing a strategy for the development of effective, high quality advocacy nationally.

4. To particularly examine advocacy and related safeguarding issues in the context of the development of new service options and the transition of existing services.

5. Advise on specific features which characterise effective advocacy.

The significance of this project was seen by the authors of this monograph to be the presentation of conceptual, theoretical and practical knowledge in relation to the nature of advocacy and the formulation and implementation of advocacy efforts. An important intent was to be instrumental in the development of a clearer direction for established advocacy efforts as well as new or planned advocacy efforts within Australia.

2.2 Description of How the Project was Conducted

Five related strategies were developed and implemented in the passage of the project.

2.2.1 Literature review

An extensive literature review was conducted in order to identify the major theoretical and conceptual underpinnings of advocacy. Much of that literature is listed in the **Bibliography** in order to provide the opportunity for readers to follow up issues of interest.

These theoretical and conceptual variables were then utilised as the basis for a framework against which advocacy efforts in Australia could be viewed and understood. It should be noted that the variables which made up this framework were not treated as fixed points of empirical reference, but were utilised as sensitising concepts which provided guidance and insights into the reviews of established advocacy efforts.

2.2.2 Reviews of established advocacy efforts

The purposes of the reviews of advocacy efforts were to test out the theoretical and conceptual framework against the actual practice of advocacy in Australia and to identify the significant issues and questions with which existing programs were concerned. At the same time, some specific issues, such as the issue of accountability and evaluation of advocacy efforts, could be explored in some depth.

The review involved the Project Coordinator visiting each of the advocacy groups and discussing issues with some of the key constituents of each. These people included some combinations of paid staff, board members and people using the advocacy effort. The review process was informal but a specific range of programmatic and non-programmatic aspects of the agency were discussed which were based on the initial identification of issues arising from the literature review and related sources.

A cross-section of advocacy efforts was selected in Western Australia, Queensland, New South Wales, Victoria and South Australia for the review process. They are described in Table One overleaf.

In addition to the 18 advocacy organisations listed in Table One, three organisations were reviewed which carry out some advocacy or advocacy-related activity. These were:

1. People with Disabilities (WA);

2. Disability Council of NSW;

3. Office of the Public Advocate (Vic).

2.2.3 Meetings with other significant stakeholders

In addition to surveying this wide range of advocacy efforts, the project also involved meetings between the Project Coordinator and a number of people and interest groups with a stake in advocacy. These included:

- HHLG&CS Disability Services Program Central Office staff in Canberra;

- HHLG&CS Sydney Disability Services Complaints Unit;

- Bureau for Disability Services in WA;

- Training for Evaluation and Change in South Australia;

- representatives from the Disability Advisory Council of Australia;

- Judith Cross who carried out a review of advocacy in South Australia;

- a wide range of people who were engaged in and/or interested in advocacy and attended the advocacy workshop in Queensland in February 1992;

- two meetings with Professor Wolf Wolfensberger during his visit to Adelaide;

- a wide range of people who attended the Wolfensberger conference;

- a wide range of people who were engaged in and/or interested in advocacy and attended the advocacy workshop in WA in March 1993;

- various consultations with Michael Kendrick during his visit to WA.

Table One: Advocacy Group by Advocacy Form

SELF ADVOCACY
Self Advocacy New South Wales Ltd
Self Advocacy Hunter Ltd (NSW)
Activ Foundation Self Advocacy (WA)
South West Advocacy Group (WA)
CITIZEN ADVOCACY
Citizen Advocacy Ryde-Hunters Hill (NSW)
Citizen Advocacy Eastside (NSW)
Citizen Advocacy Northside (NSW)
Illawarra Citizen Advocacy (NSW)
Citizen Advocacy (WA)
FAMILY ADVOCACY
The Institute for Family Advocacy and Leadership Development (NSW)
Action for Citizens with Disabilities (NSW)
Association of Relatives and Friends of the Mentally Ill (NSW)
Parent Advocacy Inc (SA)
SYSTEMIC/LEGAL ADVOCACY
Intellectual Disability Rights Service Inc (NSW)
The Accommodation Rights Service Inc (NSW)
Queensland Advocacy Incorporated
Villamanta Legal Service (Vic)
The Older Persons Rights Service (WA)

2.2.4 Visit of Professor Wolf Wolfensberger, Susan Thomas and A J Hildebrand

The Project Coordinator attended the workshops provided on advocacy during the visit of Professor Wolfensberger and his colleagues to Adelaide in September/October 1992. This provided a most significant opportunity for gaining further clarification on the nature and position of advocacy in Australia.

2.2.5 Advocacy workshop in WA

In March 1993, the Centre for the Development of Human Resources, with the support of the WA office of the Department of HHLG&CS held a two-day workshop for approximately 80 people from a range of WA advocacy constituencies. The workshop was held in conjunction with Michael Kendrick from the Institute for Leadership and Community Development in Massachusetts. The workshop had two main purposes.

1. To raise awareness of the nature and position of advocacy in our society.

2. To explore some of the critical issues, many of which were raised during the review process, facing advocacy efforts in WA and Australia.

The timetable of this workshop is provided in **Appendix B** in order to provide an overview of the format and content of the workshop.

3.0 The Nature of Advocacy

This chapter addresses the question of *"what is the nature of advocacy?"* It forms a basis for the remainder of the monograph and contains some of the fundamental assumptions which underpin the authors' approaches to advocacy. It is unavoidable when dealing with the issues in which advocacy efforts are immersed not to be influenced by one's own values, preconceptions and beliefs and in this chapter there is an endeavour to spell out some of these.

This account of the nature of advocacy begins with a description of personal vulnerability which provides a fundamental rationale for advocacy. The historical origins of advocacy are covered briefly, followed by a definition of advocacy and a description of different contemporary forms of advocacy for people with disabilities. A number of distinctions are made between advocacy and other useful and legitimate activities, and finally, the chapter provides a set of rationales for the pressing need for advocacy for people with disabilities in the current time.

3.1 The Concept of Personal Vulnerability

The Macquarie dictionary defined the word vulnerable as:

...susceptible to being wounded; liable to physical hurt; not protected against emotional hurt; highly sensitive; not immune to moral attacks; open to attack or assault; weak in respect of defence; exposed to greater than usual penalties...

Advocacy efforts occur as a response to something and cannot be understood without a serious consideration of the phenomena which they address. In fact, it is an important assumption underpinn-

ing this monograph, that a necessary requirement of good quality advocacy is a full comprehension of the human conditions and needs with which advocacy is concerned. The concept of vulnerability is fundamental to that comprehension.

Vulnerability has a number of dimensions.

3.1.1   Universality

In a real sense, all human beings are vulnerable early in their lives. Gaylin (1981), a psychoanalyst, wrote that part of the uniqueness of human beings is *"...the miserable, extended, helpless state in which we are born and remain for so long..."* (p. 3). This period of early helplessness strongly influences our view of ourselves and, possibly, also shapes our future attitudes towards people who are perceived as helpless. Gaylin asserted that a caring nature may be present in *homo sapiens* as a necessary element to ensure the development of the species.

This early helplessness could be viewed as a form of *"intrinsic"* vulnerability which is part of the human condition and experience and forms something of an analogue or very significant example of vulnerability which all humans may share. However, vulnerability will not necessarily be acknowledged or comprehended by all people. In addition to contributing to socially useful skills such as parenting, this universal experience of personal vulnerability may serve as the foundation of our capacity to understand the life conditions of other people and to have compassion and sympathy for their plight. At a societal level, the manner in which society responds to people who are vulnerable may be a clear indicator of the extent of humanity, dignity and social development of that culture. Personal responses to vulnerability may underpin a constructive sense of interdependence and encourage cooperation within social groups.

Throughout their lives, human beings may experience other occasions of personal vulnerability during which they are at risk of having a reduced capacity to conduct particular tasks or activities, including being able adequately to represent their own interests and assert their own rights. This may be a consequence of the ageing process, the occurrence of a physical or mental impairment as the result of an accident, or the loss of a loved one. Some of these periods of vulnerability are limited in time and pass. For many people, vulnerability is recognised by others around them, their friends and family, for instance, and they receive the support they need in order to safeguard them from the negative consequences of vulnerability. This support of friends and family may be seen usefully as an important model for advocacy, although it has been somewhat obscured by the reliance on formal means of helping in modern society. Some people may not have available to them the natural support of friends and family. Ferguson (1978) described this as *"social vulnerability"* in which a person may need assistance but no effective or reliable help is available, or persons who are available to help are exploitative or abusive.

A useful distinction can be made between vulnerability which is *"intrinsic"*, that is, part of the basic human condition, and vulnerability which is *"extrinsic"*, or occurs as a result of the human beings' social condition. This distinction cannot be carried too far, since all people exist in social contexts, and vulnerability which is intrinsic will be influenced by those contexts.

The World Health Organisation made a distinction between impairment, disability and handicap which provides one illustration of this point (World Health Organisation 1980). An *"impairment"* can be conceptualised as the bodily expression of vulnerability, for example, a person with a sensory impairment may have damage to organs such as their eyes, or a person with a physical impairment may have damage to their spine. A *"disability"* then is the possible functional outcome of the impairment. For example, the person with a sensory impairment may have limited vision and the person with a physical impairment

may have limited mobility. At another level or response to either the impairment or the disability, a person may experience a *"handicap"*. This places the impairment and/or disability in a social context. For example, the person's capacity to live or travel independently may be affected. Thus the response of the society, including how it views the impairment/disability and the nature of support provided is crucial in the shaping of vulnerability. This conceptualisation allows for the possibility that an intrinsic impairment need not always lead to a disability or handicap if the response to the impairment is relevant and effective.

The concepts of social vulnerability and of handicap emphasise the fundamental importance of the social environment in which people exist. The social environment may create or contribute to vulnerability in a number of ways. Vulnerability may be created by society's system of dominant values which discriminates between people who reflect those values and those who do not. For example, our society places high value on intellectual ability, health, power, wealth, youth, beauty, productivity, achievement and materialism. Some people are likely to be seen as being of lesser value than others if they do not possess these characteristics. This may then contribute to their vulnerability to various forms of different and discriminatory treatment with harmful outcomes for individuals.

Vulnerability may also be intensified if it is not recognised, or if the response to that vulnerability is inappropriate or inadequate, which then leads to certain negative consequences. In fact, some responses to vulnerability, for example the common action of removing children with disabilities from their families and communities in order to provide them with special education or with accommodation, may become one of those negative consequences. From another perspective, it has been argued that the recognition of vulnerability in modern society has become much more difficult because of the proliferation of specialised programs and actions which reflect the application of rational, reductionist and scientific thinking to human

conditions and obscures and confuses acknowledgment of personal vulnerability and individual needs (Morris 1990).

Charles Darwin (cited in Schwartz 1992, p. 59) once said:

If the misery of the poor [or other disadvantaged people] be not caused by the laws of nature, but by our institutions [or by the way society treats them], great is our sin.

It is clear from the earliest consideration of vulnerability, that issues associated with values and ideologies are central. When actions are taken in the name of, or on behalf of, people who are seen to be vulnerable, and those actions are possibly harmful to those people, a moral and ethical context is created.

3.1.2   Heightened vulnerability

Although all human beings could be said to be vulnerable, some people experience *"heightened vulnerability"* in which both the likelihood of negative consequences is much higher, and the depth and extent of those negative consequences is much greater, than for other people. It is also true that certain conditions in society are likely to increase the possibility both that a greater number of people are made vulnerable, and that the nature and extent of vulnerability is more harmful to people and to the society itself. The issue of societal conditions and their influence on vulnerability is dealt with in a later part of this chapter.

The concept of heightened vulnerability was developed in Wolfensberger's account of the "Conservatism Corollary of Social Role Valorisation", also known as "Positive Compensation for Disadvantage". In this development, the notion of society having different layers or levels is described. Society can be seen as having a

"warm core" where people who are accorded high value reside. Certain factors can then act to cause people to move outwards from that valued core to positions of risk, marginalisation and, finally, devaluation. These factors can be recognised as ageing, having or acquiring a disability, becoming ill, being unemployed etc. Thus the notion of personal vulnerability is associated with the tendency of people to experience harmful outcomes.

At the same time, other factors can be recognised which tend to retain people in the valued core of society, or which serve to protect people from further vulnerability, or even to bring them back from the margins of society. Such factors include having a job, having valued roles in society and having a network of people who provide support and friendship. **Because of the dominance of certain cultural values, some people are more likely to be vulnerable and to experience social devaluation if they are members of particular groups** (Wolfensberger 1992a).

These groups include:

- people who have impairments, disabilities and/or handicaps;

- people whose behaviour is seen to be disordered or unorthodox;

- people who rebel against the social order;

- people who are poor;

- people who have few skills or whose skills are not useful to society;

- people who are not seen to be assimilated into the culture, for example, because of race, ethnicity or religion.

Thus one source of vulnerability is being a member of one or more of these groups. **Vulnerability is heightened if a person has more than one characteristic which then places that person in more than one group.** For example, a person with a disability who is also poor and/or comes from an ethnic group, is more vulnerable. This is often called *"double disadvantage"* and is an indication of the need for priority setting for the provision of advocacy and other forms of response to vulnerability. People who have psychiatric disabilities, are poor and homeless, for instance, are arguably one of the most vulnerable groups in the community. It is widely acknowledged that a high proportion of so-called *"street people"* is made up from this group, many of whom have been *"deinstitutionalised"*.

In addition to membership of certain groups, some life conditions can heighten one's vulnerability to harmful consequences. For example, other things being equal, the longer a person remains in a vulnerable state, the greater the likelihood of harm. People who were born into a particular group whose members are commonly devalued, and people who experience a lifetime of discriminatory treatment, are more likely to experience a greater depth of negative outcomes largely because their natural defences and personal integrity are weakened or possibly destroyed by the accumulation of harmful life experiences. People who have lived in deprived institutional environments and people who have for one reason or another lost their natural carers, friends and families, live in a condition of heightened vulnerability. In a real sense, vulnerability is heightened by deprivation of continuous, close relationships. A person who has a number of friends and supporters is more safeguarded than a person who has only one supporter although of course to that person, the single supporter is crucial.

Wolfensberger described other personal characteristics which increase the chance of devaluation and discrimination: people who have physical characteristics which are not seen as typical; people who cannot reciprocate in relationships; people who are seen to be

deliberate in their violation of social values; and people who are seen as a danger to themselves, experience a heightened vulnerability.

Heightened vulnerability for people with disabilities is created also by the nature of their *impairments*. If a person has an impairment (i.e. of a physical, sensory, psychological or intellectual nature) they may intrinsically have a reduced capacity to conduct particular tasks, activities or operations. For example, a person with an intellectual impairment may have a relatively reduced capacity for some activities of a cognitive nature. They may not be able to exercise good judgement. A person with a physical impairment may have a reduced capacity for some activities of a physical nature. A person with a psychological impairment may experience a mental state or mental processes which have the potential to negatively influence his/ her perception. A person with a sensory impairment may experience some degree of sensory deprivation (i.e. unable to see as well as most people) which results in a reduced capacity to participate in activities which require the use of the sensory mechanism which is impaired.

As a result of having a *disability* a person may be intrinsically more vulnerable than people who do not have a disability. For instance, a person with a physical disability may be vulnerable to related health problems (such as kidney infections for a person who has quadriplegia). The person may be even more vulnerable in a social sense, for example, less able to defend himself/herself against physical abuse, or against loss of friendships and other support. Whilst the presence of quadriplegia may introduce certain forms of vulnerability, other types of disability may introduce other forms of vulnerability. Elderly people who are frail and have severe and multiple disabilities and may be chronically ill represent a group of people whose vulnerability is extreme. Even what may seem to strangers to be a minor setback such as being moved from one place to another can have catastrophic consequences and may even result in death.

Vulnerability may come from limited functional capacities. For instance, some people with disabilities may find it difficult to conduct the practical, everyday chores of life with the degree of independence usually expected of people of similar age and social situation. These practical tasks may include basic things, such as making a good meal, keeping oneself clean and tidy or getting across the road safely. They also may include more complex tasks such as doing one's tax return or obtaining and retaining paid employment. The consequences of limited functional capacities may be made worse because of associated poverty which may trap people in a vulnerable condition. They may not be able to afford to seek employment or because of anxiety and lack of self esteem, may not be acceptable to an employer.

The concept of heightened vulnerability is of fundamental importance in understanding the life experiences of many people with disabilities and must be acknowledged as the major part of the need which advocacy and other forms of support address. It is of grave concern that many people who are active in advocacy efforts point to the fact that the advocacy and related needs of people who are the most vulnerable in terms of having many of the characteristics described above are often least well-served.

An important implication of the concept of heightened vulnerability is the imperative of priority-setting in advocacy efforts in order to respond to the reality that some people have a greater need than others.

3.1.3 The consequences of vulnerability

To this point in the discussion on the concept of personal vulnerability, it should be clear that a distinction has been made between vulnerability and its **consequences** for people. This section addresses the common life experiences or outcomes for people who are vulnerable.

An understanding of the plight of vulnerable people is fundamental to any advocacy effort. If those concerned to provide advocacy efforts, or indeed any form of support to vulnerable people, do not comprehend the life experiences of vulnerable people, it is more probable that the response will lack relevance and effectiveness and possibly even serve ends which may contribute to increased vulnerability. A central requirement of comprehending the needs of another human being is to understand their life circumstances and experiences.

It is very difficult for one human being to put himself/herself in the position of another human being, particularly if the life experiences of the two people are very different. In order to enhance our understanding of the life experiences of others, we typically engage in certain activities. For example, one way to better understand another person's life experience is to have a lot of contact with him/her and to learn from the direct experience of a relationship with the person. Another way is to seek to identify shared or common experiences and deepen our understanding through identification with the other person. A third way is to attempt to develop a conceptual framework which attempts to grasp some of the universal or common characteristics of the experiences of others. We may thus learn more about people somewhat indirectly by studying their experiences within that framework. This is the approach of such disciplines as psychology, anthropology and sociology. Each method of comprehension is legitimate and provides different perspectives and insights. Some approaches are more likely than others to lead to a depthful understanding of the life experiences of vulnerable people.

Wolfensberger created an important and powerful learning framework in his development of *"The most common wounds of devalued people"*, which described 21 common outcomes of social devaluation in terms of the life experiences of devalued people. This framework also provides an unusually comprehensive and impactful account of the

possible negative outcomes of personal vulnerability. This information is usually provided in the context of a training workshop on Social Role Valorisation rather than in written form and, although a limited description is provided here, readers are encouraged to encounter the material in the context of a workshop.

In Appendix C we have listed contact people in Australia and New Zealand for those who wish to learn more about Social Role Valorisation.

As a result of having a physical and/or functional impairment, people are assigned a low status and social value in the society, that is, they will be considered as socially less important and less valuable than other members of the society. This will have certain consequences in the manner in which other people in the society both view and treat such people.

The most common experience will be **rejection**, both social and physical. Rejection usually involves valued people placing *"distance"* between themselves and the person who is being rejected. This distance may be physical and/or social.

Physical rejection is seen most clearly in the placement of people with disabilities in various forms of institutions, away from their families and local communities, or in the limited access provided for people that provide barriers to them simply being in the community. Rejection may be explicit, where it can easily be acknowledged, such as in institutional practices. It may also be practised with subtlety so that ordinary people do not acknowledge it, or perhaps deny it. Rejection may also be unintentional or carried out with *"good intentions"*, most commonly done *"for the good of the person"*. However, good intentions do not protect the person from the experience of rejection and its adverse outcomes.

Social rejection may include rejection by people who are close, such as family and friends in neighbourhoods and local communities. Social institutions such as the local school or the local hospital may be unwilling or unable to provide services to people with disabilities. Social rejection usually involves highlighting the characteristics of the person which contribute to their rejection. For example, by placing people with a particular type of impairment together their impairment is accentuated and becomes clear to everyone, even though a person may not wish to be identified primarily as a person with a disability. Social rejection may also be blatant as when some commonly accessible rights such as education or health care are denied to people with disabilities or at least made difficult to access, through to subtle means such as avoidance of people. Social rejection is commonly experienced by vulnerable people in the clear differentiation between themselves and the human service workers who *"serve"* them. Thus the poverty and powerlessness of vulnerable people may be starkly contrasted with the resources and power of the human service systems.

Another set of consequences involves **loss of control** over different aspects of one's life. For example, persons may not be able to choose where or with whom they live; where or even whether they work; whether they can fully develop their socio-sexual identity; or perhaps they may lose control over more everyday choices such as what time they rise in the morning and go to bed at night, or the type of food they eat. In a culture which values autonomy, freedom and independence, these experiences are especially negative.

A common experience for people with disabilities is to have imposed on them many short-term relationships, especially with people who are paid service workers. This discontinuity in relationships is often accompanied by many physical movements in their lives, particularly in connection with where they live, and it is especially associated with being located within a formal human service system. These discontinuities over which vulnerable people have no control may result in them not developing certain social skills and in develop-

ing emotional problems such as debilitating levels of anxiety. It is then common for these functional disabilities to be seen as characteristics of the impairment rather than as shaped by life experiences.

People may lose control over their reputations which may be shaped by their presence in a particular human service or their membership in a particular group about which there are strong stereotypes. For example, people with psychiatric disabilities have little control over the stereotypes which are held about such disabilities which may shape the perception that they are dangerous. People with intellectual disabilities are often perceived as lacking certain moral characteristics which mean that they are more likely to be seen as perpetrators rather than as victims of crime. Having a physical disability may mean that aspects of one's socio-sexual identity are denied.

Many consequences of social devaluation are associated with loss. For example, freely-given relationships may be lost and replaced by paid relationships; there may be a loss of personal, individual identity, particularly if one is viewed principally as one of a group of people with similar characteristics of impairment; there may be loss of certain experiences which other people in the society value and take for granted; and loss may involve involuntary poverty. The essence of the experience of loss is **the substitution of low status, devalued roles for valued roles**. Wolfensberger uses the term *"life wasting"* to reflect that for many people, what they lose is a valued life.

Finally, vulnerability may lead to people experiencing **brutalisation** which may include having physical harm and damage inflicted upon them, and even may result in loss of life. The issues of abuse and *"death making"* are of profound importance, particularly in the context of advocacy (Wolfensberger 1987). Concern about these matters is increasing and is indicated clearly by various publicity and reports on abuse of people with disabilities, both in formal human

services and in the community (Elvik 1990; Johnson 1988; Morgan 1987; New South Wales Law Reform Commission 1992; Parker 1991; Tharinger, Horton and Millea 1990; Verick 1991).

3.1.4   Responses to vulnerability and its consequences

Two broad responses to personal vulnerability and social devaluation are described briefly here.

Informal Responses

The first is the provision of **informal responses** such as those provided by an individual's natural networks of support. The natural support network includes one's family, friends, neighbours and acquaintances. For most people, this is the first line of defence against vulnerability and devaluation and, as mentioned above, provides something of an analogue or model of how people support one another in a social context. To this can be added the naturally-occurring networks of community resources, associations and social institutions, such as leisure outlets, cultural opportunities, schools and churches.

Various phenomena in late twentieth century Western society have been identified which provide a threat to the capacity of these informal networks of support. This account is not in depth or exhaustive, merely indicative. These phenomena tend to interact and intensify effects so that it is not always clear which factor is/was the primary influence. The phenomena which place limitations on the availability of carers include:

- the development of a *"post technological"* society with changing patterns of work (Bell 1973; Michael 1983; Toffler 1980; Williams 1982);

- changes in socio-demography, particularly in relation to the increasing proportions of older people (American Association of Homes for the Aging 1984; Commonwealth Department of Community Services and Health undated a; Commonwealth Department of Community Services and Health undated b);

- changes in family structures such as:

    a)   increased proportions of one-parent families;

    b)   the physical dispersal of the extended family, the traditional source of support, due to increased mobility;

    c)   indications of increasing stress within families, such as high rates of marriage dissolution and spouse abuse (Dalley 1988; Edgar 1992; Ferguson 1978; Finch 1989; Lagergren 1985; Walker 1987);

- the accelerated development, particularly since the Second World War, of formal human services with an associated strong influence of professionalism, bureaucracy and technology within that development (Cocks 1987; Cocks 1992; McKnight 1976; Wolfensberger 1987a).

Each of these influences acts to weaken the capacity of informal structures to respond to personal need.

Formal Responses

The second response to vulnerability and social devaluation is the **formal response** of society which is contained in the provisions of a **legal framework** and in **formal human services**. Both provisions are underpinned by an important assumption that the state, meaning

government in the broad sense, has a responsibility and an obligation to provide support in one form or another. One of the origins of this belief is the doctrine of *"parens patriae"* which perceives the state as playing a paternal role in relation to some of its citizens, especially groups of citizens who are identified as vulnerable.

In the early eleventh century enactments of the Anglo-Saxon King Aethelbed II was a statement of the king's responsibility towards his subjects.

If an attempt is made to deprive any wise man in orders of a stranger of either his goods or his life, the king shall act as his kinsman and protector...unless he has some other.

<div align="right">

(Kittrie 1971, p. 9)

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It is interesting to note that the king's role was conceptualised as like a *"kinsman"* or relative and this provided the model. In medieval England, responsibility for certain groups in need was held by the family, the church and the lord of the manor. From the seventeenth century, in connection with the Agrarian and Industrial Revolutions, many welfare functions slowly shifted to the state. The various Poor Laws from 1536 through to 1834 represented attempts to deal with the growing numbers of vulnerable people. The Poor Law of 1834 was described as:

...the most important piece of social legislation passed in the nineteenth century. It established a new model of administrative machinery — nationally centralised decision making on substantive issues of policy, professionalised civil servants, bureaucratic rationality. In essence it was the first recognisably modern welfare system.

<div align="right">

(Marcus 1981, p. 53)

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In the twentieth century, the welfare state has evolved into a vast, complex system which serves many purposes and is subject to growing critique (Beilhartz, Considine and Watts 1992; Fitzgerald 1982;

Gaylin et al 1981; Graycar 1983; Habermas 1989; Illich 1977; McKnight 1986; McKnight 1989b; Mishra 1984; OECD 1981; Szasz 1974; Wolfensberger 1975). It is beyond the scope of this monograph to provide a full account of this critique. However, because it is central to the issues of the relationship between advocacy and formal societal responses to vulnerability, a brief account will be provided.

The welfare functions of the state have a number of manifestations and serve a number of primary purposes, some of which can be seen to be conflictual. The most common manifestations of the welfare state are seen in legislation which attempts to deal with particular social problems associated with certain groups of vulnerable people, for example, poor people, people who are unemployed, people who are ill, or people who have disabilities. This legislative framework, consisting of, for example, social security acts, mental health acts, and disability services acts, provides for a range of different types of human services which comprise the more direct response to the needs of people. This service system includes not only those services actually provided by the state, but also those provided by the voluntary and private sectors, each of which is strongly influenced by government funding and other mechanisms of regulation such as licensing.

In terms of purposes, the modern welfare state objectives include both protecting the vulnerable person from harm either from himself/herself or the community, and protecting the state or community from the vulnerable person. **This is a situation in which conflict is bound to occur, particularly where the interests of the individual and the community do not correspond and may even be in opposition.** A third common objective relates to human and social development. Thus the welfare objective may aim to promote human growth and development or to foster independence, and to achieve a fairer, more equitable or just society. A fourth objective includes a range of economic functions including the provision of employment and various economic multiplier effects which have become very important to modern economies since the enormous growth of formal

human services post-World War Two. A fifth objective is the maintenance of the existing social structure by ensuring that established social stratifications and power relationships are not threatened.

It can be seen that a range of interests are represented in the operations of the welfare state function and that these interests often will be in conflict, with the likelihood that in many situations, the interests of the weaker parties may not win out. At the heart of the conflict is the state's paramount need to maintain a certain social order and to protect the **society,** an objective which will almost necessarily conflict with the needs of individuals at different times, particularly if those individuals are viewed as socially deviant.

The legislative and human service manifestations of the welfare objective of the state have grown enormously in the second half of the twentieth century, both in terms of size and complexity (McKnight 1986). For example, not only have the traditional welfare-oriented legislative efforts become more complex but new areas of legislation have emerged, particularly over the past decade or so. To the traditional areas of social legislation such as mental health, criminal law, community welfare, children, youth and families must be added relatively new pieces of legislation including legislation related to anti-discrimination, equal opportunity, guardianship, ombudsmen and related administrative appeals, freedom of information, and various areas of public health. The legislation and associated regulations represent a very significant widening of the state's perceived and actual responsibility towards groups of citizens who are vulnerable.

As well as the burgeoning and widening of the social legislative mandate, there has been an associated growth in the provision of formal human services which represent the attempt to establish a comprehensive service system to address the needs of an ever-increasing number of identified groups of vulnerable people. It is historically unprecedented for there to be such an investment of

finance, human and physical resources devoted to such a range of formal organisations with the stated brief of alleviating human suffering and need. The characteristics of this system represent a strong reliance on bureaucratic forms of organisation, high levels of specialisation and professionalism and the application of various forms of machine, managerial and service technology to create a situation of immense and opaque complexity.

To provide one example of this issue, the Department of Social Security's profile in 1986-87 contained the following statistics:

* $16.1 billion in payments to 5 million clients;

* In 1986, 100 million payments were made;

* A departmental structure of 8 State/Territory headquarters, a central office, 217 decentralised regional offices and 17 area offices;

* Almost 17,000 employees representing nearly a 50% increase over the past decade;

* Identified problems faced by the Department included: communication within and outside the Department; the quantity of instructions (an average of one instruction **per day** was issued from Central Office alone in 1986); staff training needs with 50% of staff under 30; design and delivery of stationery, systems, computer programs, forms, documentation etc; and so on (Volker 1987).

To complete the example, these major problems were to be addressed by the development of various technical communication means: program budgeting; the Financial Management Improvement Program which includes the use of an ADP (automatic data process-

ing) system; office automation systems linking the regional offices to augment the Stratplan On-Line Information system, and so on. As Volker (1987) wrote:

In the complex environment in which we now work, "risks" do not always pay off. For example, a last minute risky fix to address a problem with a very small number of cases in the Northern Territory resulted in a problem for the majority of cases nationally. Many of these sorts of problems are being addressed, but sometimes the solutions themselves can create a potential for even wider problems.

(p. 84)

Three important sources of critique of the formal societal response to vulnerability and social devaluation are particularly relevant to advocacy.

First, the growth and extensions of the *parens patriae* doctrine can be seen as intrusive and even coercive, allowing the state to intrude increasingly into areas of private life. The concept of the *"therapeutic state"* (Kittrie 1971; Szasz 1974) is seen as a specialised product of the welfare state and has involved increasing over time the number of different groups of people which come under its control and responsibility. Some forms of human difference, such as aging, being young, having an impairment, having difficulties managing certain life challenges, smoking and being pregnant, have been redefined from being expressions of acceptable social variation and difference, to being an expression of need for therapeutic intervention in order to reform or rehabilitate the person.

This line of critique is concerned about certain outcomes of the extension of *parens patriae* and the development of a state-determined comprehensive formal system of human services.

One outcome will be in the **intolerance of society towards certain forms of human diversity.**

The therapeutic ideal thus presents society with a choice. Do we want to abandon our privacy and diversity, and the constitutional safeguards thereof, for a world in which there is maximum security from physical harm and where there are no deviant persons to offend our sensibilities? Or do we want to preserve the traditional ideals at the risk of crime and untoward behaviour by part of the populace?

(Kittrie 1971, p. 351)

A second outcome will be **increasing power and influence being wielded by the machinery of state**, for example:

In such a system, public officials, called administrators, bureaucrats, or civil servants, settle certain disputes in accordance with rules made, not by legislators, but by the administrators themselves.

(Szasz 1974, p. 216)

A third outcome will be in **poor treatment of vulnerable people**.

The record of public charity is an unloving record of punishment, degradation, humiliation, intrusion, and incarceration. If parents treated their children the way society treats the helpless, they would be cited for neglect and child abuse. The power of 'lovability', which normally saves the child from disaster, has no precise social analogue.

(Glasser 1981, p. 123)

A fourth outcome will be the **growth of dependence and learned helplessness** as people are treated as children within a parental model.

....those in need of help were more or less like children. The disadvantaged were the objects of care, they were to be done for. They did not require protection against the well-meaning parent, rights to be exercised against the paternalistic state.

(Rothman 1981, p. 70)

Finally, an outcome will be the **disengagement of the informal helping system and the breakdown of community.**

Whenever hierarchical systems become more powerful than the community, we see the flow of authority, resources, skills, dollars, legitimacy, and capacity away from communities to service systems. In fact, institutionalised systems grow at the expense of communities.

(McKnight 1988, p. 11)

The **second** line of critique, drawn from the first, examines the relationship between individual rights and the growth of formal human services within the welfare and therapeutic states. This argument focuses on the cost to the rights and integrity of the individual of protecting him/her from himself/herself and from the community, and protecting the community from the person. Recipients of welfare processes are subject to forms of procedures and controls in exchange for certain benefits and are also subject to attempts to *"improve"*, change or rehabilitate them. This is particularly the case if the nature of the vulnerability and need is seen to include lack of capacity or competency.

It is of interest to note that it is only relatively recently that the rights of recipients of various forms of welfare effort have been seen from the perspective of freedom and liberty as opposed to *"right to treatment"*. Compared with other groups of human service clients, for people with disabilities this emphasis has been little more than a decade old.

The rights issue contains a real dilemma in terms of the conflict between limiting paternalism and overprotection for people with disabilities on the one hand, and avoiding a denial of real need on the other. There is always the danger that a single-minded pursuit of individual rights might rationalise the neglect and abandonment of some vulnerable people.

The **third** area of critique addresses the contradiction between the stated objectives of formal human services so far as they attempt to promote such virtues as personal independence, freedom, self-actualisation, social integration, growth and development, each commonly encountered in the mission statements, aims and policies of human services and the state, and the means used to achieve those objectives (Cocks 1987; Habermas 1989; McKnight 1989a). This critique is fundamental and examines and analyses the primary dependence of modern formal human services on bureaucracy, professionalism and technology, concluding that these methods are counterproductive to the stated objectives around individual human development and lead to incoherency and conflict within formal human service systems. In addition, these means utilise very large amounts of resources which maintain systems of delivery which channel those resources away from people who need them.

Each of these critiques of the formal societal response to vulnerability and social devaluation and the problem of the roles and capacity of informal systems, provides an important context for advocacy efforts. **Advocacy efforts must contend with both a powerful formal response to human vulnerability which is inherently conflictual and at times actually counter-productive, and a weakened informal system of support.** *It is also clear that careful distinctions must be made between efforts made by formal systems that may be legitimate but do not constitute advocacy.*

Finally, these critiques form a powerful rationale for the primary responsibility of governments which have created and sustained these comprehensive, formal human service systems. The nature of this responsibility entails an acknowledgment of the limitations and dangers of these systems both for vulnerable people and for the capacity of communities to respond positively, and the need to support efforts to safeguard against these debilitating influences. Advocacy is one of those efforts. This important issue will be addressed further below in the context of the roles of governments in advocacy.

3.1.5   Some implications of personal vulnerability for advocacy

At this point it is useful to identify a summarising set of principles which are derived from an understanding of the concept, nature and experience of personal vulnerability in the particular context of the formal responses of society to personal vulnerability. These principles begin to define the issues that advocacy is intended to address. Some of these principles are drawn from "The Conservatism Corollary or the Concept of Positive Compensation for Devalued Status" which is one of the seven themes of Social Role Valorisation (Wolfensberger 1992a).

1.   Personal vulnerability and its consequences create the need for and focus of advocacy efforts.

2.   Understanding the concept, nature and experience of personal vulnerability and its consequences provides the necessary foundation of advocacy efforts.

3.   Although all human beings experience occasions of vulnerability in their lives, some individuals and groups of people are especially likely to experience **heightened vulnerability** and the consequences of **social devaluation and disadvantage** which are of a different and more intense quality and quantity than other people experience. These individuals and groups of people are often identifiable even before vulnerability leads to obvious negative consequences for them.

4.   It is possible to identify certain factors, including personal characteristics and life experiences, which contribute to heightened vulnerability, and then to develop safeguards and *"lines of defence"* which avoid or minimise negative outcomes and impacts for people.

5.   Advocacy efforts have a major and central role to play in countering personal vulnerability and devaluation through actions taken by advocates on behalf of and in the interests of people who are vulnerable.

6.   Informal responses to personal vulnerability such as those provided by family, friends and neighbours are an important analogue and model for some advocacy efforts.

7.   Formal responses, which largely have been developed and supported by governments, through protective services and human services are adequate in addressing some needs that are created by personal vulnerability and social devaluation. However, some aspects of formal responses, particularly those which are associated with the need to serve interests other than or in addition to those of the vulnerable person, mean that *"independent"* advocacy is required.

8.   It is clear that some individuals and groups of people experience even greater intensity of personal vulnerability and social devaluation than others. The greater the extent of personal vulnerability and/or social devaluation, the greater is the need for an advocacy response. Advocacy efforts should reflect some setting of priority, and awareness of the existence of people with needs even greater than those of people they are serving.

3.2 Historical Roots of Advocacy

According to Wolfensberger, advocacy has its roots in at least three ideological/social movements (Wolfensberger 1977). The **first** of these is the Judeo/Christian belief system which, through the Old and New Testaments admonishes "*...the safeguarding and protection of*

the lowly, the orphaned, the widow...the weak, the sick, handicapped and abandoned". Wolfensberger pointed out that although support for Judeo/Christian denominations has markedly decreased in modern times, the belief in altruism and support for people in need is still held as an important social ideal and thus strongly influences human behaviour and the development and practice of social policy.

The **second** source of advocacy is the Hegelian/Marxist ideologies which are *"built upon the twin pillars of equity/egalitarianism and materialism"* (Madigan 1992). This philosophy is seen as providing strong directions for the development of societies which are more just and equal and which support the development and self-realisation of the individual. Notions of egalitarianism and a *"fair go for all"* have been powerful sentiments in Australian culture, possibly with only limited success, but still providing an influential ideal. Most Australian governments profess policies of social justice and access and equity and have enacted a range of enabling legislation around anti-discrimination and equal opportunity within the past decade. Most Australian formal human service organisations in government and non-government sectors espouse similar intents and policies both for their paid staff and often for their clients.

Within the Hegelian/Marxist ideologies, advocacy movements are *"...conceptualised as the antithesis of an established power or interest which is seen as detrimental to the individual or group"* (Wolfensberger 1977). One illustration provided by Wolfensberger draws attention to the words used by many advocacy movements which reflect this idea — words such as *"...class struggle, the people, workers, masses, the enemy, the oppressors, establishment, aggression, reactionaries, liberation, power, the cause, coalition...".*

The **third** source of advocacy emerges from the realisation that formal human services have very significant inadequacies arising from the major conflicts of interest inherent in their objectives and practices and their increasing complexity and formalisation. These

issues have been canvassed in the preceding section. Thus advocacy is seen as necessary to safeguard and protect the interests of people who need and/or use formal human services.

In the years since the Second World War, there have been a number of influences on the disability field which are particularly relevant for advocacy efforts.

The emergence of the parent movement occurred in the late 1940s and early 1950s in many parts of the Western world, including Australia (Cocks 1989; Cocks 1990). This movement was based in part on the questioning by many parents of the institutional alternatives for their children and also the rejection of their children by those educational services which were freely available to non-disabled people. This was a powerful movement which challenged many negative stereotypes and expectations about people with disabilities and it led to the development of what has become a vast and complex formal service system in the non-government sector in Australia and other parts of the world. It is an interesting observation that the development of this service system has to a significant extent reflected the same conflicts inherent in so-called *"parent advocacy"* between the needs of the person with a disabilities and those of the parents/family. Thus many services address the needs of families as a priority over the fundamental needs of people with disabilities. This is not to say that parents and families do not have legitimate interests that should be addressed by specific advocacy efforts and services, but it does mean that not all of those interests correspond to the interests of people with disabilities.

A second influence on the disability field and on advocacy in particular has been the human rights movement which gained great prominence in the 1960s through the civil rights movement in the USA. This movement has lead to enormous sensitisation in many countries, in addition to the United States, to a range of issues around individual rights and the place of minority groups within society.

The 1960s saw the development of many movements including the civil rights movement in relation to black people, the women's movement, and anti-poverty movements (Freeman 1983; Paluski 1991).

The United Nations Declaration on the Rights of Mentally Retarded Persons was one of the earliest statements of the application of the rights movement to disability. It was followed by the Declaration on the Rights of Disabled Persons. The International Year of Disabled Persons in 1981 furthered these directions for the broader group of people with disabilities.

One expression of this general movement towards rights for minority groups in Australia is the profusion of enabling legislation in Australia which is based on a rights model, both generic, as in equal opportunity acts, and specialised, as in various disability acts.

A further influence on advocacy development has come from the articulation of a number of influential principles within human services. Some examples include:

- Normalisation (Wolfensberger 1972; Nirje 1985);

- The Least Restrictive Alternative (Burgdorf 1980; Turnbull 1981);

- The Dignity of Risk (Perske 1981; Wolfensberger 1972);

- The Developmental Principle/Model (Wolfensberger 1992a);

- Social Role Valorisation (Wolfensberger 1983b; Wolfensberger 1992a).

Finally, the self help movement is closely related to advocacy efforts. The self help movement is largely based on the assumption that people who have had, or are experiencing the same life circumstances, can provide mutual support, understanding and a

desire to change things to improve their lives (de Meyere 1985; Jezewski undated). Self help is particularly concerned with developing self actualisation, skills for independence, and ensuring that people develop and maintain maximum control over their own lives. Self help is a concept closely related to self advocacy and in fact self advocacy may be more appropriately conceptualised as self help rather than as advocacy. This issue is discussed further below.

3.3 Definition of Advocacy

The Macquarie Dictionary (1989) defined the term *advocate* in more than one way, depending upon the context in which the word is utilised (ie. as a verb or a noun).

When used as a **verb** (ie. I *advocate* for them) the dictionary defines the word as meaning to *"plead in favour of; support or urge by argument; recommend publicly"*.

When used as a **noun** (ie. she/he is an *advocate*) the Macquarie Dictionary defines the word as meaning *"one who defends, vindicates, or espouses a cause by argument; an upholder; a defender....; an advocate of peace"*.

The Macquarie Dictionary (1989) defined the **act** of Advocacy as *"an act of pleading for, supporting, or recommending; [an act of] active espousal"*.

Recently, Wolfensberger (1992b) defined advocacy as:

Functioning (speaking, acting, writing) with minimum conflict of interest on behalf of the sincerely perceived interests of a person or group, in order to

promote, protect and defend the welfare of, and justice for, either individuals or groups, in a fashion which strives to be emphatic and vigorous.

This definition will serve as the key statement of meaning for advocacy in this monograph. The various elements of the definition, particularly its emphasis on minimum conflict of interest and its focus on action, will be examined in greater depth.

3.4 Contemporary Forms of Social Advocacy for People with Disabilities

Based on Wolfensberger (1992b), three approaches to advocacy for people with disabilities can be described, each distinct in terms of methods and outcomes and sharing some commonality of stated' objectives.

1. Informal/normative approaches to advocacy.

2. Advocacy within human service systems.

3. Legal advocacy.

3.4.1 Informal/normative approaches to advocacy

The primary example of informal/normative advocacy is the role of family members or friends in standing up for another family member or friend who is vulnerable or actually being treated unfairly. When one person stands beside, or stands up for, someone who is close to them, this would be described as a highly personal, natural and informal approach to advocacy. This type of advocacy does not involve

agencies, human services, formal networks or people who are being paid to conduct advocacy.

Advocacy may be considered natural, informal and highly personalised when it is provided by a person who:

a) is close to the person who requires advocacy support;

b) knows the person very well;

c) cares about the person;

d) is involved in some form of relationship (i.e. friendship) with the person.

The methods of informal/normative advocacy utilise actions which are seen by people as ordinary, recognisable, familiar and within the capacity of almost all people to exercise. Often the methods reflect the manner in which a person might stand up for, or defend themselves in situations of personal vulnerability or threat. Some common ways in which one person might provide another with this form of advocacy support might include: *"speaking up, making their presence felt, complaining, keeping after people; raising a ruckus, writing letters, whistleblowing, threatening to sue, taking direct personal action, etc".* (Wolfensberger 1992b)

Natural, informal and personal advocacy is a culturally normative act which is strongly embedded in our culture to the extent that:

1) it is accepted, if not expected, that people should stick up for those close to them when it appears that they need this type of support;

2)   this type of advocacy occurs very often (i.e. people often stick up for other people);

3)   this type of advocacy occurs in a variety of places (i.e. people may advocate with or for their friends in a variety of settings such as: at work; in public; in court; in public places; etc).

This form of advocacy can also involve an individual advocating for more than one person, for example, a group of people with disabilities, or can involve more than one person advocating for an individual. However, if this advocacy is to be truly informal, natural and personal then it still must meet the criteria outlined above.

In regard to the effectiveness of informal/normative advocacy, Wolfensberger commented:

Culturally normative [natural and personal] relationships are far superior to paid ones. They are independent and can do things an unfree paid worker can't do.

(Wolfensberger 1992b)

In addition, in many situations, people in need express that they prefer the informal support of people close to them rather than other more formal types of support which can be provided by professionals or others less close to them.

Although personal, natural and informal approaches to advocacy can be highly effective, often constitute the first preference of people, and are culturally appropriate, this form of advocacy often receives the least support, if any.

As stated by Woodson (cited in Schwartz 1992, p. 115):

It has been clearly demonstrated that informal networks (mediating structures) have the strength to solve a range of social problems that have defied solution by

traditional bureaucratic organisations. Yet public policy continues to ignore these indigenous institutions and instead vests most of its resources in the institutions that [people]...rank as their last choice. (emphasis added)

It is noteworthy that this expression of advocacy occurs independently of the formal interests of organisations, systems and governments.

3.4.2   Advocacy within human service systems

Advocacy occurs in a multitude of ways within formal human service systems and this approach to advocacy has burgeoned in recent decades. Four expressions of this form of advocacy are described here:

(i)   the state as advocate;

(ii)   independent public advocacy programs;

(iii)   non-independent advocacy programs;

(iv)   public interest advocacy.

(i)   The state as advocate

Examples of the state, or governments, as advocates are associated with the *parens patriae* doctrine which was described in an earlier section of the monograph. They include the development and implementation of social policies, establishment of legislation, and direct and indirect provision of actual services. Under the doctrine of *parens patriae,* the role of the state has clearly widened during this century to include not only a *"safety net"* function for vulnerable people, but also a more pro-active role in what might be called *"social*

engineering". The latter role would encompass actions taken by the state which are intended to serve both preventative and rehabilitative functions. Many of the activities of the state in this area are described as *"protective services"*.

Adult protective services refer to a range of measures including social policy, legislation and human service provision intended to address the needs of adults who have diminished physical, social or mental functioning which may be associated with age, disease, injury, mental illness and/or intellectual disability. A key issue in such services is to respond to various manifestations of personal vulnerability. This may include possible endangerment from one's physical and social environment, vulnerability associated with the lack of capacity to care for oneself or adequately represent one's own interests and rights in everyday living situations, and vulnerability which might arise from having no effective, reliable or non-exploitative personal support.

The concept of adult protective services involves responses to vulnerability in the context of a *"system"* of services. Thus:

Adult protective services is one level of a comprehensive adult service system. It is a full-access service that is distinguished by the "protective" characteristics of the person served and uniquely, but not in every instance, involves a modulated substitution of the client's decision-making power by that of another person who is willing to use professional authority as well as legal and judicial authority to secure or to provide necessary medical, social, or legal services based on the least restrictive alternative and gradualism...

(Ferguson 1978, p. 37-8)

Ferguson described four functions which make up the *"core system"* of adult protective services. They included outreach investigation and assessment; use of surrogate authority; follow-up and monitoring; and, most importantly from the perspective of clar-

ifying the nature of advocacy, she included *"advocacy"*, described as exploring options and linking clients to services.

A central question to be addressed is whether advocacy fits usefully within such a formal, systematised response, or whether it is important to distinguish such activities as something other than advocacy — legitimate and constructive, but different from advocacy. It is vital that this issue be clarified in the context of deciding the nature of advocacy in order to avoid various confusions which may weaken or disadvantage true advocacy efforts, such as supporting and/or funding an activity as advocacy when it really serves different needs and ends.

At least two characteristics of the state's role vis-a-vis vulnerable people raise the question of which activities can legitimately be seen as advocacy and which are not.

First, much of the state's activities in regard to vulnerable people are highly formalised through both legislative and human service frameworks. The issue is whether or not the extent of formality is a dimension along which different advocacy activities are placed so that some activities might be seen as more or less formal, or whether the advocacy intent is defeated by activities which lie beyond a certain level of formality. This is an important issue which will be taken up again later in the monograph.

Second, the state obviously has interests in addition to those of the vulnerable person to protect. The issue here is whether the unavoidable conflicts of interest which are intrinsic to the state's welfare objectives mean that it cannot act in the sole interests of any single person or group, especially if that person or group is relatively powerless. The issue may be refined to whether or not **some** state activities can constitute true advocacy, for example, through providing support to the advocacy efforts of others.

(ii) Independent public advocacy programs

From around 1966 there has been an increasing interest in the notion of public or quasi public advocacy programs for people with disabilities. The interest and support for these types of advocacy programs have their roots primarily in the USA, where, in 1969, the National Association of Social Workers initiated a committee which discussed advocacy. At the same time Professor Wolf Wolfensberger had formulated an approach to advocacy for people with disabilities which has since been called *"citizen advocacy"* which is discussed in some detail below (Wolfensberger 1973; Wolfensberger 1983a; Wolfensberger and Zauha 1973).

Experimental advocacy programs were established in Nebraska in 1969 and 1970 based upon the ideas set out by Wolfensberger. Since then, many citizen advocacy schemes and other forms of advocacy have been set up in Australia and throughout other parts of the world.

These forms of advocacy are intended to be independent from the interests of the state and of human service providers although they may receive support, particularly financial, from sources of funding which are connected with service provision. These advocacy efforts address the needs of individuals and/or groups or classes of people with disabilities. Their focus may be on supporting individuals and/or on changing other systems of support such as formal services or legislation.

An associated form of advocacy is parent or family advocacy which may incorporate advocating directly for people with disabilities or may involve advocating for the needs of parents or families. A further form of group advocacy consists of organisations which represent specific groups of people with disabilities such as the Down's Syndrome Associations, Prader Willi Syndrome Associations, or the broad group of people with disabilities such as Disabled Persons International. These represent different types of advocacy, which, although having some overlap, essentially involve different interests.

Within Australia, the Commonwealth Government has enacted legislation, (the Disability Services Act 1986), which provides support and funds for the establishment of a range of different forms of advocacy programs for people with a disability. These advocacy programs include: self advocacy; citizen advocacy; parent advocacy; and group advocacy. The Commonwealth Government's description of these various advocacy forms is provided below (Department of Health, Housing, Local Government and Community Services 1986). It is clear when reading these descriptions that advocacy is conceptualised under the legislation as a *"service"*.

Self Advocacy

Self advocacy services assist people with disabilities to develop and maintain the personal skills and self confidence necessary to enable them to represent their own interests in and become a recognised part of the community.

It aims:

- *to assist people with disabilities to develop skills, knowledge and confidence so that they can advocate on issues on their own behalf and become a recognised part of the community as a whole.*

Citizen Advocacy

Citizen advocacy services facilitate people in the community to assist people with disabilities to represent their own interests and establish themselves in the community.

It aims:

- *to arrange and support relationships between people with disabilities and non-disabled people who otherwise would not meet;*

- *to ensure that the interests of the person with disabilities are represented by the advocate;*

- *to assist people with disabilities to live more independently and establish themselves within the community;*

- *to broaden the social network and community participation of people with disabilities;*

- *to enhance the ability of people with disabilities to speak for themselves and to ensure that their rights are exercised and safeguarded.*

Parent Advocacy

Parent advocacy services assist families of people with disabilities to represent their interests in the community.

It aims:

- *to provide support to individual families to assist them to advocate on the behalf of their disabled family member;*

- *to help parents identify local priorities and to see the broader aspects of disabilities and rights issues, including ensuring that the Principles and Objectives of the DSA are being met by the [other] human services [which their son/daughter may be using].*

Group Advocacy

Group advocacy services facilitate community organisations to represent the interests of groups of people with disabilities.

It aims:

- *to raise awareness in the non-disabled population of the needs and special difficulties faced by people with a disability and where necessary to bring about changes in existing systems and services;*

The service provided may be short term advocacy on a single issue for an individual, or a system advocacy where the primary input is by an agency or a system in respect of a group of service users. Both types of group advocacy may be provided by one organisation.

It is noteworthy that the descriptions of advocacy objectives and activities directly reflect the legislation from which funding support is provided. For example, there is a strong emphasis on *"community"* and *"independence"*. This is a good example of how advocacy efforts are shaped by additional interests and needs. This is not to say that the principles and objectives of the particular legislation are not very positive and desirable, but the legitimate question is raised as to the nature and relative priority of the various interests which are served.

(iii) Non-independent public advocacy programs

Many human service organisations have in-house advocacy programs. These in-house advocacy programs may seek to provide advocacy to individuals with disabilities and/or to groups of people with disabilities who use the service. Commonly, such programs are focussed on self advocacy and aim to provide opportunities for the development of skills, knowledge and confidence to enable people to advocate on their own behalf. These groups may be developed around a particular service they utilise and be called, for example, a *"workers' committee"* or a *"residents' committee"*.

A major issue with these forms of advocacy is the extent to which

they are shaped and influenced by the *"parent"* body so they are actually a component of the formal service itself. These efforts may have limited effectiveness because of the conflict of interest of the auspicing human service organisation. Inevitably, the organisation will be faced with the dilemma of whether they can support individuals, even if they are the clients of the service, who are critical of the organisation. The natural tendency will be for the system to ensure its own protection and continuation. There is also a danger that the character of the auspicing body will subvert the objective of advocacy, for example, by inserting a *"training"* culture into the advocacy group or by shaping the activities of the group to reflect the formality of the service system.

Another form of non-independent public advocacy organisation is represented by bodies such as the National Council on Intellectual Disability which represents both service providing organisations and people with intellectual disabilities, and the Australian Council for the Rehabilitation of the Disabled, which represents various formal service providers.

(iv) Public interest advocacy

Public interest advocacy involves a person or group taking a stance on issues which are coherent with the interests of the public at large, or a strata or segment of the general public.

A well-known example of someone who has advocated vigorously in the public interest is Ralph Nader who was considered in the *Economist* in 1971 as having *"done more as a private citizen for the...(United States) and its people than most other public officials accomplish in a lifetime."* Nader's work was prolific and addressed a range of public issues including the environment (Acton and Lamond 1972); bureaucracy and the establishment (Franklin and Trotter 1974); political economy (Green 1973); and consumerism (Marshall 1971). A perusal of Nader's

work and writings provides a rich source of purpose, strategy and tactics for advocates.

"Whistleblowers" may also be considered public interest advocates and at times governments contemplate legislation to protect such people.

The Australian Consumer Association (ACA) is an example of a public interest advocacy organisation which aims to provide people who are consumers with information and guidance in relation to goods and services, and also represent and lobby on behalf of consumers. ACA raises its funding primarily through its publications and thus manages to operate relatively independently. Similar advocacy bodies include Greenpeace and various environmental groups.

3.4.3   Legal advocacy

The legal system provides another approach for advocacy and protection for people with disabilities and other members of Australian society. Legal advocacy, as it is represented by the relationship and contract between the legal practitioner and his/her client, is one of the oldest and most systematic of advocacy efforts. It is notable for the strict ethical rules which govern this relationship, especially in regard to conflicts of interest of legal advocates.

In the context of the criminal justice system, it is clear that people with disabilities, particularly those with intellectual disabilities, are personally very vulnerable (Cockram, Jackson and Underwood 1992; Johnson, Andrew and Topp 1988; New South Wales Law Reform Commission 1992). This vulnerability is manifest in two ways. First, people with disabilities may be more vulnerable to having crimes committed against them if they lack various social skills and experience because of their impairments and/or life experiences. Second, they may lack understanding of the law and thus be unaware of the

rights and protections offered by legal means. In any case, they face the same experiences of the general citizenry, particularly in regard to the complexity and expense of legal processes.

The needs of people with disabilities for adequate personal legal representation has been clearly recognised by Principle 6 of the United Nations Declaration on the Rights of Disabled Persons. This Principle states:

Disabled persons shall be able to avail themselves of qualified legal aid where such aid proves indispensable for the protection of their persons and property. If judicial proceedings are instituted against them, the legal procedure applied shall take their physical and mental condition fully into account.

In addition to addressing issues of personal vulnerability, legal advocacy may address the area of legislation, for example, enabling legislation such as disability services acts, generic legislation such as equal opportunity acts, and specialised legislation such as adult guardianship acts. It is clear that the area of pertinent legislation has become very complex over the past decade or so, and the need for legal advocacy to ensure that the interests of people with disabilities are well represented is crucial.

A good example of a legal advocacy body is Queensland Advocacy Incorporated (QAI), a state-wide, independent advocacy organisation based in Brisbane. The membership of QAI is mostly people with disabilities and management is comprised of a majority of people with disabilities. QAI's mission is to *"empower all people with a disability"*.

QAI provides legal advice; promotes law and policy reform; provides rights and legal education; and provides assistance to individuals and groups to take action in standing up for their rights. QAI has been a significant influence in the debate around relevant legislation, for example, adult guardianship legislation in Queensland

and has developed an important discussion paper on the subject. Similar bodies exist in New South Wales and Victoria.

3.5 Distinctions Between Advocacy and Other Useful Activities

It is important to distinguish between activities and efforts that constitute advocacy and those which do not. In attempting to make such distinctions, one must identify the essential characteristics of advocacy that are coherent with a definition. Such an analysis does not mean that activities which are called advocacy and which do not meet the requirements, are not useful activities.

The reasons why it is important to make distinctions between advocacy and other activities include the following.

First, it is important to develop clarity in order to reduce confusion about our understanding of the nature of advocacy. The authors contend that the human service field has become enormously complex in recent years and this has greatly contributed to uncertainty and even incoherency in the purposes and activities which have developed around people who are vulnerable or who are socially devalued. There is a need to be clear about what advocacy is, even to be clear about the elements for which there is controversy or disagreement.

Second, when activities which are not advocacy are called advocacy, a situation akin to Aesop's fabled *"dog in the manger"* is created. In essence, the advocacy *"ground"* is limited and must not be *"occupied"* by activities which have different purposes and outcomes. An obvious result when this does occur, is that true advocacy efforts are discouraged and not supported.

Third, if we are clear about what advocacy is, the possibilities of perversions are reduced and the advocacy effort is strengthened. For example, if activities which serve to foster dependence and/or strengthen interests which are not primarily concerned with the interests of vulnerable people (for example, the interests of formal service providers or funders), are promoted as advocacy, the true advocacy movement becomes more confused and is weakened.

Finally, the clearer the understanding of the nature of advocacy, the more likely it is that issues associated with accountability, evaluation (if appropriate), standards and ideals, and funding (if appropriate) will be addressed coherently. For example, if funding agencies believe advocacy is primarily another manifestation of formal human services, they are likely to require the same types of accountability mechanisms and even to label and fund advocacy efforts as they would another service. Equally likely, activities which are not advocacy are likely to be funded as though they are advocacy.

Again it must be emphasised that the position taken here does not deny necessarily the validity and value of different activities, but asserts the vital importance of understanding the distinctiveness of advocacy.

3.5.1   Essential characteristics of advocacy

The issue to be addressed here is whether there are particular characteristics which are **necessary** for an activity to be called advocacy, and also whether there are characteristics which are **preferred** but not necessary. To begin with, Wolfensberger's definition provides the baseline.

Functioning (speaking, acting, writing) with minimum conflict of interest on behalf of the sincerely perceived interests of a person or group, in order to

promote, protect and defend the welfare of, and justice for, either individuals or groups, in a fashion which strives to be emphatic and vigorous.

This definition has a number of elements.

(i)   Advocacy incorporates basic human activities of speaking, acting and/or writing.

(ii)   Advocacy involves *minimising* conflicts of interest. Thus advocacy may involve some measure of conflict of interest, but the definition requires that this be minimised. This supposes that there is high consciousness of the issues associated with conflicts of interest and that action is taken to reduce them. It might also be inferred that some types of conflict of interest are more or less inappropriate than others. The issues associated with conflict of interest are analysed further below.

It is also implied in considering issues associated with conflicts of interest, that the advocacy effort is **clear about the individual or group for whom it is advocating**. It is obvious that if there is confusion about this, conflicts of interest are much more likely to occur.

(iii)   Advocacy means acting on behalf of **another** person. This element of the definition draws into question the concept of self advocacy. If one acts on one's own behalf, a more accurate term might be *"self help"* or *"self-determination"* or some similar term. As discussed above, the self help movement historically predated the development of what is called self advocacy for people with disabilities.

(iv)   Advocacy addresses the interests of another person or group of people who are *"sincerely perceived"*. This characteristic requires the advocacy effort to be *"grounded"* in knowledge of the per-

son/people and include awareness that it is those interests with which advocacy is concerned and not the interests of others.

(v)   Advocacy activity is proactive in *"promoting"* interests, preventative in *"protecting"* interests, and assertive in *"defending"* interests. The nature of advocacy activity is definite and energetic.

(vi)   Finally, advocacy is concerned with both the welfare of the person/persons and also with their rights in the sense of seeking social justice, equity and fairness.

In addition to these characteristics, in concordance with many people who are active within the area of advocacy, we believe there are some additional characteristics of advocacy.

Advocacy should be based upon a vision of a just and fair world. This vision should be underpinned by a strong values base which asserts the dignity and worth of people with disabilities and other vulnerable and disadvantaged people. This vision and values base should be explicit and the people concerned with the advocacy activity should have internalised the values. **In addition, the advocacy effort should be grounded in an understanding of the realities of vulnerability and social devaluation for people, particularly those for whom the advocacy is being carried out.**

This conceptualisation takes a broad view of advocacy in supporting the notion that advocacy efforts, even if they be for one particular person, are part of a broader striving towards well-being, justice and equity for particular disadvantaged groups in society. Thus advocacy is linked closely with a high consciousness of the reality of social inequality for many people and a desire to alleviate that inequality.

This does not mean that appropriate and productive activities cannot be carried out on behalf of, or for, people with disabilities by people who do not work from a coherent values base, a close knowledge of the issues, or an identification with the broader social advocacy movement. In this conceptualisation of advocacy, however, such activity would be called something other than advocacy.

Engagement in advocacy may be costly for advocates in many possible different ways. The cost may be financial; in devotion of time; in loss of career advancement; in terms of other relationships; and may even involve the marginalisation of or harm to the advocate.

Finally, because of the nature of the personal and societal conditions that are addressed by advocacy efforts, **advocacy is likely to require a long-term process and involvement.**

3.5.2   Activities that may not constitute advocacy

Wolfensberger (1992b) has described a number of activities which are often called advocacy but may not be.

(i)   People may act as change agents in their work to reform, modify and change systems. Although this activity may be coherent with advocacy and may even serve advocacy ends, change agentry is not, in itself, advocacy.

(ii)   Measures which are concerned with enhancing service quality may be consistent with the purposes of advocacy, but do not constitute advocacy. Service evaluations or accountability mechanisms such as licensing or minimum standards will provide benefit to people with disabilities in services and may even be measures which can be utilised by advocates, but they do not in themselves constitute advocacy.

(iii) Advocacy and protective measures differ. For example some people such as children, need protection but not advocacy. People may receive needed protection from formal services, but those services will not necessarily stand up for, or act solely in the interests of service users.

(iv) Case work services are not advocacy particularly because they often pursue the interests of society and service systems.

(v) Advocacy services which are *"in-house"* and provided by formal human services do not constitute advocacy as defined here and may contain very considerable conflicts of interest. Such services might be a useful part of the formal human service but should not *"occupy the ground"* of independent advocacy.

(vi) Friendship, although providing a useful analogue for some aspects of advocacy, does not in itself equate to advocacy. For example, some friendship may be quite passive and have certain conditions attached involving conflicts of interest which are considerable.

(vii) Complaints mechanisms may be utilised by advocates, but in themselves do not constitute advocacy.

(viii) There are a number of new service types such as service brokerage and coordination which operate within formal human service systems and thus do not constitute advocacy.

(ix) Self advocacy presents a particular set of issues in considering whether it constitutes advocacy, or may more accurately be termed self help, or even simply called *"sticking up for"*, or *"speaking up for oneself"*. If advocacy is considered as acting in the interests of or on behalf of *another* person or group, the term *"self"* advocacy becomes illogical. In practice, there are at least two

major issues which arise from the actual activities of many self advocacy groups.

First, the heightened vulnerability of many people with disabilities means that they may be placed in situations of greatly increased risk if they are encouraged to challenge powerful interests without adequate support from advocates and other allies. Relatedly, it is not uncommon for those who encourage people with disabilities to speak for themselves to be perceived as manipulative and serving their own ends. These are not arguments, of course, for denying the importance of people with disabilities having the right and opportunity to be self-determining and speaking for themselves, but it does point to the difficulties of this process.

Second, a common criticism of self advocacy agencies is that they do not result in much meaningful advocacy, but primarily provide people with disabilities with development of skills, the support of other people who share similar life experiences, a source of recreation, and/or a friendship network. Each of these functions is very important but does not constitute advocacy. It may be less confusing for these activities to be identified for what they are, for example, self help or social skills development.

Again it needs to be stated that all the above activities may be legitimate and useful but do not in themselves constitute advocacy as defined here.

3.6 The Great Need for Advocacy for People with Disabilities

It is the view of the authors that in the present times the need for advocacy for people with disabilities and other disadvantaged people is at least as great as it has ever been and probably greater. Four fundamental rationales are provided in support of the pressing need for advocacy. **These must be seen in conjunction with the intrinsic vulnerabilities of people with disabilities and they serve to magnify those vulnerabilities.**

3.6.1 Dominant cultural values

Certain dominant cultural values can be identified in modern society which may be inimical to the interests of people with disabilities. For example, a preoccupation with materialistic and utilitarian values means people who are seen as unproductive or relatively dependent, or people who have limited possessions or money, are likely to be seen as being of lesser value than others. Modern society is fiercely competitive and concerned for quick, *"instant"* responses, disadvantaging people who cannot fulfil associated expectations because they require time to respond. Values associated with hedonism and individualism will influence the treatment of people who may be perceived as offending aesthetic ideals, or people who need care and obstruct the pursuit of personal gain.

This does not mean that other values such as altruism and human respect and dignity which affect people with disabilities positively do not operate. Nor does it mean that all people abide by the dominant values described above. However it does mean that the influence of these values operating through powerful institutions such as the media, formal human services and public education, is very considerable and constitutes one of the primary forces driving social devaluation.

3.6.2 Societal turbulence

Societal turbulence refers to social change which has certain characteristics which add to the general level of stress and dislocation in society generally, and more specifically serves to further disadvantage particular groups within society. Some writers refer to the current era as *"post-industrial"* or even *"post-technological"* (Bell 1973; Cocks 1987; Michael 1983; Toffler 1980; Toffler 1990; Williams 1982).

The characteristics of change in this situation include:

- a very fast pace of change with changes occurring constantly and often too quickly for people to comprehend and assimilate the new order;

- change which is occurring virtually simultaneously in many different areas of life — for example, in dominant cultural values, in fundamental and respected social institutions such as the family, and common patterns of living such as work;

- change which is leading to greater complexity, uncertainty and unpredictibility.

Information about what happens to cultures undergoing such profound change is freely available in historical accounts of times of change such as the Reformation and the Agrarian and Industrial Revolutions. In every case, through increased vulnerability and its consequences, certain groups of people tend to carry the burden of change and dislocation more than others. Such groups include those who are vulnerable because of the transitional nature of their status (such as youth and elderly people) or people who already possess significant vulnerability, such as people with disabilities. In addition, during such times support that occurs naturally through the family or the neighbourhood is less responsive to need because of pressures on and changes in the patterns of informal caring.

In such turbulent times, vulnerability is intensified and the need for advocacy is increased.

3.6.3 The limitations of the response of formal human services

Certain characteristics have developed within formal human services that intensify the need for advocacy. These characteristics include an almost opaque complexity resulting from the profusion of *"new"* services and the adoption of technology within services; a growth in formalisation and bureaucracy associated with the large size of human service organisations and the passage of time since their initial development; and the dominance of professionalised approaches to supporting people. Each of these constellations of characteristics *"calls forth"* advocacy efforts.

These characteristics are a result of many factors, in particular:

- the pressures on formal human services to respond to the growing social problems, crises and dislocations which are occurring because of societal turbulence;

- the phenomenal growth in formal human services, especially in the relatively short time period post-World War Two, which has contributed to high levels of formalisation and bureaucracy;

- following a dependence on incremental budgetary increases to fund both growth and reform of formal human services, the economic climate has altered towards more stringency and reinforced a so-called *"values-free"* culture of rationalism and pragmatism;

- dominant cultural values.

Over the past decade in particular, the pace of apparent reform in formal human services has accelerated and there has been a profusion of *"new"* service types across the service spectrum, including methods of defining and assessing need, accommodation services, vocational services and, of course, in advocacy efforts. In addition, there have been many inquiries and reports, new policies and new legislation. The disability field has become immensely more complex than even a decade ago. This has been accompanied by a growth in the actual number of services, although it is unclear whether this is related to an increase in actual service user numbers. Many of these *"innovations"* are highly technical and some are untried. Many are aimed at introducing greater control and accountability and introduce instead more complexity and utilise more resources which are diverted from services. Most come from good ideas and intentions.

The need for continuity, stability and predictability has probably never been as great. The task of advocacy here is to try to ensure that changes are in the interests of people with disabilities and to safeguard people with disabilities from possible harm in such a turbulent environment.

The rapid growth of formal human services has been accompanied by increasing formalisation and bureaucracy. Although the classical characteristics of bureaucracy may be appropriate for some purposes, in the context of providing support to vulnerable people, many of the characteristics are at least questionable. For example, modern bureaucracies in human services represent a move from:

- charismatic and visionary leadership;

- flexible division of labour;

- high membership access and involvement;

- high goal orientation towards people;

- focussed and relatively straightforward program structures;

- interpersonal climates of enthusiasm and commitment to people;

towards:

- proliferation of leadership positions emphasising technical competence and *"portability"* of skills;

- high levels of discontinuity in key staff and increasingly, in direct-service staff;

- rigid division of labour within complex industrial constraints;

- high levels of boundary-oriented professionalism and specialisation;

- considerable goal displacement especially towards organisational continuation;

- significant levels of staff confusion and dissatisfaction (Resnick 1992).

In addition, human service organisations have grown greatly in size, sometimes through *"conglomeration"* of organisations and services, and most experience almost constant restructuring and instability.

An important outcome of these directions has been a significant *"crisis in faith"* by some key stakeholders in formal human services, including people who use services and people who work in them. This is an environment in which people with disabilities are much more likely to need the support of independent advocates.

3.6.4 Social policies and practices which increase the risk for vulnerable people

There are many social policies and practices which increase directly the risks for people with disabilities. These are well documented (Wolfensberger 1987). The nature and extent of these risks for a number of vulnerable groups such as elderly people and people with mental illness as well as people with disabilities is being described and acknowledged increasingly in the professional literature (Callahan 1988; Crystal 1987; Deveson 1978; Diessenbacher 1989; Elvik, Berkowitz, Nicholas, Lipman and Inkelis 1990; Fitzgerald 1982; Hickson 1991; Mason 1984; Morgan 1987; Tharinger, Horton and Millea 1990; Weicker 1987).

People with disabilities are particularly vulnerable to social policies associated with euthanasia, abortion, sterilisation, deinstitutionalisation, health care, human tissue donation, educational provision, transport, housing and so on.

Given the current turbulence in society and its institutions, advocacy which can clearly act in the interests of people with disabilities is of paramount importance.

4.0 Principles of Advocacy

Based closely on the work of Wolfensberger, five principles which underpin advocacy efforts are described below. These governing principles provide a set of guidelines that both characterise and provide direction for advocacy. These principles are:

1.   advocacy is on the side of the disadvantaged person/people;

2.   advocacy is concerned with genuine life needs;

3.   advocacy strives to minimise conflicts of interest;

4.   advocacy engages in vigorous action;

5.   advocacy has fidelity to disadvantaged people.

4.1 Advocacy is on the Side of the Disadvantaged Person/People

Advocacy groups find themselves having to respond to many external pressures and influences that come from a range of stakeholders and their interests. For example, stakeholders in the advocacy effort may include people with disabilities, funders, board members, advocates, community members, families, human service workers and so on. Each stakeholder has particular interests. Funders may be concerned primarily with accountability for allocated funds. Governments may seek an efficient and effective response from the advocacy movement to influence their policies. Board members may have a primary interest in how the scheme operates and in the continuation of the organisation. Families may primarily be interested in what an advocacy scheme can do for a son or daughter.

Stakeholders may wield a great deal of power and influence over the advocacy effort to the extent that some stakeholders' interests may hold sway over others. In the usual run of political events within human services and the wider community, the more powerful or influential interests will prevail. **It is important to appreciate that the interests of stakeholders may be legitimate in their own right. However, the nature of advocacy and the needs of people with disabilities combine to determine the principle that advocacy efforts should always be on the side of the primary stakeholder — the person with a disability.**

Other endeavours, for example, formal human services or groups that advocate for other interests such as parents, families or staff, will serve the interests of those other stakeholders, but advocacy for people with disabilities is for people with disabilities.

This does not mean that on occasions the interests of people with disabilities and other stakeholders may not correspond. Nor does it mean that on occasions the advocacy effort may not be mistaken in its interpretation of what constitutes the interests of a person or group of people with a disability. **In both cases, given the vulnerability of people with disabilities and the intent of advocacy, great care should be taken to ensure that the interests are clearly identified and the advocacy scheme does not compromise its stance in order to appease the interests of other stakeholders.**

Associated with this principle and the concept of vulnerability, advocacy efforts should be concerned with the needs of people whose vulnerability is greater. Such people may have multiple disabilities or associated disadvantages such as poverty or old age or they may be institutionalised, ill or imprisoned.

During a visit to Australia in 1990, Michael Kendrick commented on the increased vulnerability of people who have either a more severe disability or who have a double disadvantage. If such people live in environments which are segregated from society, they often are less able to complain or seek redress if their rights or integrity are violated. In a similar vein, Wolfensberger (1983) observed critically that citizen advocacy programs appeared to less frequently serve people with more difficult problems such as those associated with more severe impairments than with mild or minimal impairments.

Underpinning this point is the need for advocacy efforts to be aware of priority groups and their needs. Even if the needs of more disadvantaged people are not addressed directly, the advocacy effort should be conscious of them. In a sense, this would *"ground"* the advocacy effort and develop a sense of solidarity with disadvantaged people generally.

Discussion with advocacy groups in Australia revealed awareness of the importance of the principle of minimising conflicts of interest, and also that many advocacy schemes felt a major external influence on their efforts came from the interests of funders and their outcome requirements. This is a complex issue as the requirement for accountability for the use of external, particularly public, funds is quite legitimate. A frequent concern from advocacy groups was the appropriateness of the outcomes sought. Often they were primarily quantitative (for example, the number of *"matches"* effected between people with disabilities and advocates) and couched in terms more fitted to a formal human service. The issue of accountability is addressed in more detail in a later section of this monograph.

4.2 Advocacy is Concerned with Genuine Life Needs

Human needs can be defined in many ways. This principle asserts that advocacy should be focussed on important needs rather than minor or inconsequential needs. There is an implication in this principle that advocacy resources are not abundant and therefore should be concentrated on more significant rather than less significant needs.

One distinction which would be made if this principle governed the activities of an advocacy group, is that of **urgency** of need. Urgent needs may correspond to the so-called *"lower order"* needs, posited by Maslow (1943), which are seen as having priority over other, higher order needs. For example, if a person is not receiving adequate food and drink, or adequate physical safety or security, then that person's life may be in danger. Satisfying these lower order physiological or security needs would take precedence at any point in time over higher order needs such as leisure or recreational needs or the address of needs for more independence or self-actualisation. Addressing higher order needs in fact may not be possible unless urgent needs are first met.

A second important distinction is between **major** and less important needs. Major needs are those which, if addressed, have the greatest potential to affect the person's life positively. Advocacy efforts would be concerned to focus efforts on major life needs in order to maximise positive outcomes for the people.

An imperative associated with addressing genuine needs is acting in the best interests of the person with a disability. In the current dominant value system of our culture which emphasises individualism, self-determination and independence, the idea of one person acting in the best interests of another individual seems paternalistic unless the individual determines his/her own interest. This is likely to

be the case. However, advocacy efforts must be prepared to sometimes act in what they believe to be a person's best interests, even though the person may not express their interest in the same way. To deny this issue is to work from the assumption that people always know what is in their best interest, which is plainly incorrect as a general principle. A person with a disability may be less than completely aware of his/her own best interests because of certain life experiences that result in deprivation. The person may be less able to use the benefit of experience. He/she may be unable to make any major life decision at all as a result of having lived much of life within a large, segregated institution. This may include being able to make an informed decision about whether or not it is in his/her interests to continue to live in an institution. An advocate may play a key role in identifying and addressing that which is in the person's best interests.

Alternatively, one may work from the assumption that if people are mistaken in determining their own best interest, that is their own fate. However, the nature of advocacy is a concern for the vulnerability of people and a desire to ensure they do not come to harm.

This is clearly a difficult principle and it might be expected that advocacy efforts are keenly aware of the associated issues and have developed ways of safeguarding their decision-making to minimise the chance that they will be wrong in their judgement of what is the person's best interest.

Wolfensberger coined the term *"mistaken advocacy"* to mean advocating for the wrong things and described some guidelines which may help avoid this occurring (Wolfensberger 1992b).

1. Gain an understanding of hierarchies of need and the differences between fundamentality and urgency of need.

2. Study in depth the nature of oppression, social stratification and social devaluation.

3. Develop a deep knowledge of and insight into the person for whom one is advocating and into the group or class of people of which that person is thought to be a member.

4. Ensure that there is a closeness between the advocate and the person/group for whom the advocacy is taking place. This closeness should include actually being with that person/group frequently and in different situations to ensure that person/group is known.

5. Gain an understanding of the person's interests, wants and needs from the person to the greatest extent possible.

6. Learn about the interests of other parties who have an involvement with the person for whom one is advocating in order to understand how that may influence the expression of the person's interests.

7. If one is advocating for a group, determine whether there is sufficient commonality of interests for group advocacy to be possible without mistaken advocacy occurring.

8. Clarify how one's own world view and interests might influence the advocacy process and conclusions made about the person's best interests.

4.3 Advocacy Strives to Minimise Conflicts of Interest

Conflict of interest refers to situations in which two (or more) valid principles clash and cannot co-exist (Wolfensberger 1977). Conflict of interest is one of the most critical issues facing advocacy efforts and is ever-present. Some examples of common conflicts of interest that occur in advocacy include the following.

1. What is good for the advocacy organisation may not necessarily be good for the person/people for whom the advocacy is carried out. For example, the advocacy organisation may be motivated or driven to grow larger, more bureaucratic or raise funds in ways which are questionable. Commonly, the organisation may undertake other functions such as information dissemination or provide policy or other advice in service to government or formal human services. These situations are likely to adversely affect the focus and quality of advocacy and to create conflictual roles for the organisation.

2. Major, influential stakeholders in the advocacy process may require the advocacy effort to be directed in certain ways that may serve interests other than those of the person/people for whom advocacy is intended. For example, it is difficult for advocacy to be fearless in the face of disapproval from funding bodies. Outcome requirements of funding bodies may bring pressure to increase the size of advocacy efforts and may determine what are seen to be legitimate activities. Families may seek outcomes which are at odds with the needs of family members with a disability.

3. Within an advocacy effort, the needs of different people for whom advocacy is provided may conflict. For example, the needs of one person may require twice the resources of another

and the advocacy organisation would have to decide between two competing and legitimate needs.

4. Commonly, the needs of the advocates will conflict with the needs of the person/people for whom advocacy is provided. For example, the timing of an advocate's holiday may not suit the interests of the person. The advocate may have pressing family needs to attend to which may limit his/her availability.

The complexity of the issues of conflict of interests is illustrated by the following account of some of the principles which need to be understood (Wolfensberger 1992b). For each of these principles, an advocacy organisation wishing to be rigorous about minimising conflicts of interest would need to develop strategies and safeguards to address them.

1. Conflicts of interest can have a large number of sources and there can be even more interests at stake in an issue than have been identified.

2. It is likely, especially over the long run, that people will pursue their own interests.

3. Conflicts of interest are likely to be greater in number and more intense the greater the number of parties involved in an issue.

4. The more pluralistic a society is, the greater the diversity. Different interests and associated conflicts of interest are likely to occur more frequently in a highly pluralistic society such as our own.

5. Some conflicts of interest arise from legitimate interests and appropriate motivations on the part of advocates and others. Thus, even committed and moral parties must expect to have conflicts of interest on some issues.

6. Some conflicts of interest can be very subtle and may not involve overt conflict.

7. Conflicts of interest tend to undermine objectivity regarding an issue and to reduce whole-hearted commitment.

8. A real conflict of interest occurs even when people are confident they can rise above it or when they do not consciously acknowledge that a conflict exists.

9. An advocacy effort that includes some significant conflicts of interest must expect to be compromised, at least over the long run.

10. The suggestion or appearance of a conflict of interest can sometimes be as harmful as an actual conflict.

11. One can engage in mistaken advocacy or be wrong on an advocacy issue even if one does not have conflicts of interest.

If an advocacy effort is to address the interests of a person with a disability, then it is of fundamental importance that every attempt is made to identify and minimise the conflicts of interest that are occurring or may occur.

During the reviews of Australian advocacy efforts associated with this project, a number of particular conflicts of interest were identified which were having an impact.

A.   Paying the piper who calls the tune.

A number of citizen advocacy programs commented that some of the expectations of government funders conflicted with the interests of people for whom the programs provided advocacy. As part of

funding contracts, programs were required to demonstrate that they could support a particular number of new matches between advocates and proteges per year. This quota of new matches was pre-set as part of the funding contract.

There was general acknowledgment of the need to demonstrate that new matches were occurring, but it was felt that the quota set was often ambitiously high and applied rigidly. One consequence of this was to influence advocacy efforts towards people for whom matches were easier to achieve. Providing advocacy for people with more significant impairments, greater needs or a double disadvantage, thus becomes more difficult to achieve.

B.   Not biting the hand that feeds you.

A number of advocacy schemes which had occasion to stand in contradiction to formal human service systems or government funders felt an understandable apprehension that their actions could result in repercussions for their advocacy organisation. A key issue here is jeopardising the funding and other support which advocacy organisations receive. Clearly, repercussions could occur wherever the supporting body has an interest which the advocacy effort opposes or resists, even if the resistance is in the interests of people with disabilities. The critique of formal human services described in an earlier section of this monograph that relates to the multiple purposes of those services is relevant here.

In principle, this conflict suggests at least two strategies. First, sources of funding and other support for advocacy efforts should be as far removed as possible from the vested interests of formal human services and of government funding agencies which are concerned with funding those services. Second, a wider funding base must be developed in the effort to reduce the conflicts that come with government funding.

C. Letting the fox manage the hen house.

Most advocacy organisations had human service providers on their boards of management. This was supported by comments that human service workers on boards were able to add insightful and useful perspectives to the workings of the boards. It was also commented that human service workers considered issues from ideological and values perspectives that were sometimes at variance with what some advocates believed should be the underpinnings of advocacy efforts.

In some situations, the role of a *"dissident"* human service worker who has *"inside"* knowledge of the workings of formal services may be a great asset to an advocacy effort. The central issue here relates to the cohesion and coherency exhibited by advocacy efforts. Ideally, all persons involved in the advocacy effort, including board members, should share a common perspective and understanding of advocacy.

Staff of human service organisations who serve on advocacy boards may experience conflicts of loyalties if the services with which they are concerned provide services to actual or potential persons for whom the advocacy is provided. Safeguards should be established to ensure that if the board of an advocacy organisation is comprised of some human service workers, that they should not be closely aligned with those services. The general principle would also apply that if any board member is unable to meet the criteria of having as his/her highest priority, the interests of the person/s with disabilities, they should not remain on the board.

The presence of human service workers on the boards of advocacy organisations can affect the perceived legitimacy or independence of the effort because of the suggestion or appearance of conflict of interest.

D. Can I personally do what needs to be done?

Some advocates are uncomfortable about standing in contradiction to the service system. This was expressed by comments such as *"we are getting on much better with the human service organisations now"*, or *"we are rarely in conflict with the services now"*.

Although over-escalation of conflict is undesirable, there will inevitably be many occasions when advocacy efforts will be in conflict or questioning of formal human services. If the advocacy effort has an objective of *"getting on well"* with service organisations, it is probable that there is a reduced will to be vigorous in defence of the interests of people with disabilities when they do not correspond with those of more powerful interests.

A related issue is the need for advocacy efforts to have sufficient independence from services to be able to identify incoherencies and inconsistencies in services which impact badly on people with disabilities and to be able to act with independence.

4.4 Advocacy Engages in Vigorous Action

The notion of *"vigour"* when used in relation to advocacy means the level of energy and/or force used to conduct activities which address the interests of people with disabilities.

The degree of vigour required by an advocacy organisation may vary in accordance with the level of demand required to conduct a particular task or activity. Weak defence of the welfare and interests of people with disabilities would obviously be considered weak advocacy whilst vigorous defence would be considered strong advocacy.

Advocacy efforts may be weakened for a number of reasons.

1. The advocacy effort may have become desensitised to the extent of oppression and disadvantage of people with disabilities or perhaps never was sufficiently sensitised.

2. The advocacy effort may not have gained a full insight into the life and experiences of people with disabilities or perhaps denies the reality of social devaluation which is associated with disability and thus is not properly focussed or energised.

3. The advocacy effort may have become spread too thinly over too many people to be able to operate vigorously for any one person.

4. The advocacy effort may have been co-opted by the systems and structures which it should be concerned to advocate against in the interests of people with disabilities.

5. The advocacy effort may have become unable to identify where the vigorous advocacy is needed and may waste its energies.

6. The advocacy effort may become listless or even uncaring.

4.5 Advocacy has Fidelity to Disadvantaged People

Fidelity refers to observing commitments and promises, providing loyalty and being faithful. The need for fidelity is seen as particularly important for people with disabilities because their common life experiences are of discontinuity in both their personal relationships and physical environments. Discontinuities create situations in which sustained commitments cannot occur and people with disabilities are let down.

Relationship discontinuity commonly occurs through the large number of paid relationships that people with disabilities experience within human services because of a number of factors including high staff turnover and even agency practices which discourage close or ongoing relationships between staff and clients. People with disabilities often have to leave their families and neighbourhoods and the important relationships that occur there, in order to receive services.

Physical discontinuity commonly occurs within residential services as people with disabilities are moved from one setting to another for many reasons. Policies of moving people to address their changing needs is more likely to occur than modifying services. During the advocacy workshops in Adelaide in 1992, A. J. Hildebrand gave an example of a sixteen year old girl with disabilities who had lived in 35 different homes in her short life, contributing to extreme discontinuity in both relationships and environment.

Advocacy efforts in particular must have fidelity to people with disabilities, not only to counter the insecurities of people, but also in order to know them well enough to accurately identify their needs and best interests. Advocacy efforts should be prepared to operate within a long-term time perspective because it is only within that time-frame that promises and duties towards people with disabilities can be fulfilled.

5.0 Key Issues in Australian Advocacy

A number of key issues were identified during the reviews of advocacy and advocacy-related efforts. It should be emphasised that not all issues were experienced or acknowledged by every advocacy effort. However, the following analysis is an account of a set of key issues concerning advocacy in Australia at the present time.

5.1 Values

Given the nature of advocacy and the needs which advocacy efforts address, it is crucial that advocacy bodies are as rigorous as possible in ensuring that they are working from a base of values and principles which are consistent and coherent with the best interests of the person/people with disabilities about whom they are concerned. The values base should be well thought out and clearly explicated. There should be well developed processes within the advocacy body to regularly review and renew the values base and to ensure that the values base is understood and supported. This is not an easy process, nor one that can be carried out in a short time or done only once.

The authors strongly support the point that advocacy efforts should be governed by values and principles which are of high order. Such values are not tied to societal trends or fads but are usually enduring and serve as important guides over the long term. This means that some values should take precedence over others because they are more important. For example, an advocacy effort might place a higher priority on action associated with human life and dignity than it would on the importance of individual wants or desires. An advocacy organisation might take a stance against the closure of an institution and the placement of its residents into the community if it believed that this might lead to personal harm to those people. The nature of advocacy inevitably will require advocates to take positions that are not widely supported or popular, but which do reflect careful consideration of the **right** or moral stance that should be taken. If the advocacy body has not clearly thought through its values base and firmly established its governing principles, it may be unable to act vigorously or it may be more likely to act mistakenly to the detriment of the people for whom it is advocating.

5.2 Vision

In addition to a clearly explicated values base, advocacy efforts need to have a vision of what they are aiming to achieve in the long run. In her recent report on advocacy schemes in South Australia, Judith Cross wrote:

Each advocacy group needs to have a vision of what society should look like if there is to be true justice for people with disabilities. It does not make sense for movements for societal change to not have a view on how things should be different. Advocacy groups need to be clear about the vision they have of what needs to change in our society for people with disabilities. They need to have a vision, a direction, something they are standing and striving for, and it is this that should guide the actions of the group.

(Cross 1992, p. 16)

In addition to a vision of society, advocacy efforts must be guided by a vision of an ideal life for people with disabilities within that society. If the personal vulnerabilities, devaluation and disadvantages often experienced by people with disabilities were addressed and rectified, a vision of life would likely be an *"ordinary life"* which is experienced by valued people in the culture. This vision of an ordinary life can be a powerful motivating force.

The development of a vision that is shared between the stake-holders of an advocacy effort will serve to keep the effort focused and energised. Where a vision was encountered in Australian advocacy efforts, it revolved around issues such as equity, equality, access-ibility, social acceptance, empowerment, social justice and inclusion for people with disabilities.

5.3 Advocacy as Social Movement or Human Service?

This issue is concerned with the question of whether advocacy is primarily a service similar to, but not necessarily the same as, a service that provides accommodation, respite or work for people with disabilities, or whether advocacy is a movement for societal change for people with disabilities.

If advocacy efforts are viewed primarily as human services, they will adopt objectives, structures, processes, and seek outcomes, which are similar to those of human services. An examination of the terminology of legislation and accountability mechanisms of many existing advocacy efforts strongly suggests that they are viewed by some stakeholders as human services.

Some characteristics of human services may correspond with advocacy efforts. For example, some human services may address the recognised needs of people, their efforts may be based on positive values, and they may have a commitment to protect and promote the well-being of people in their services. However, some characteristics do not correspond with advocacy as it is defined in this monograph. For example most human services have a substantial, sometimes a primary, responsibility to other key stakeholders such as staff and

society, utilise paid, professional staff who operate within formal structures, and so on.

A further perspective is that which conceptualises human services as essentially *"mediating structures"* between the predominant or agreed values, beliefs and customs of the society, and individuals who are seen to require support. Thus human services inevitably reflect predominant social values and interpret and reflect these in the way they define and address human needs. Given the needs of people who are vulnerable, often to those very predominant values of the society, and the needs of people whom society has devalued and disadvant-aged, there is a very strong argument for advocacy maintaining, to the greatest extent possible, an **independence** from dominant societal values where these clearly disadvantage people with disabilities. This does not mean that advocacy efforts must be anti-social, but they must be free to take a position which is at odds with dominant societal val-ues and beliefs if that is in the interests of people with disabilities.

A comprehension of the history of the treatment of people with disabilities provides powerful examples of this issue (Rosen, Clark and Kivitz 1977; Scheerenberger 1987; Wolfensberger 1975). For example, during the late nineteenth and early twentieth centuries, people with disabilities were considered to be a social menace. The dominant cultural values and beliefs, strongly supported by the ex-pert knowledge of the time, perceived people with disabilities as an economic burden and as purveyors of vice and degeneracy. This led to people with disabilities being placed in large, dehumanising institutions and to programs of sterilisation that reflected the intent of the eugenics movement. This movement reached a peak in Germany in the 1930s during which many tens of thousands of people with disabilities were killed (Gallagher 1990). At other times, people with disabilities have been and still are viewed as child-like or as sick, each a reflection of dominant cultural values and beliefs. In each case, the human services provided by society for people with disabilities were

shaped by, and were consistent with, those beliefs. These were times when independent advocacy was desperately needed.

The historical experience of people with disabilities strongly supports the argument that advocacy should not be conceptualised as a human service. In fact **the capacity of true advocacy efforts to stand apart from dominant cultural values and beliefs when they are seen to be harmful to people with disabilities, may be a crucial characteristic of advocacy.** Associated with this point is the need for advocacy to be guided and governed by relatively high order and enduring values rather than those which reflect short-term trends or values which are popular.

It is a reasonable observation that advocacy efforts cannot effectively operate to safeguard people with disabilities from imperfect human services if the advocacy efforts themselves are immersed in the same ideologies and cultures as those services. If advocacy schemes are formulated and established within the same parameters as human services and are then forced to utilise the concepts, language and practices of the human service sub-culture, then it is predictable that advocacy will increasingly look and operate like a human service.

5.4 The Need for Informal Advocacy

As discussed in **Section 3.4.1**, informal advocacy has certain characteristics which distinguish it from advocacy which may be paid and/or operate in conjunction with formal systems. Informal advocacy is culturally normative and thus easily understood by ordinary people. In some circumstances, informal advocacy is the preferred approach because it consists of methods which are familiar

to people, and because it addresses some needs which formal advocacy cannot address.

Informal advocacy efforts which engage and mobilise ordinary people in standing up for and standing beside people with disabilities are vital in building supportive communities and countering the great dependence of society on formal services. In spite of this, informal advocacy is not fostered or encouraged to the same extent as formal advocacy efforts.

Developing strategies to support informal advocacy presents considerable complexities and challenges. For example, the conditions associated with some forms of financial support may alter the essential informality of the advocacy effort. The nature of informal advocacy will change if it is linked too closely to formal systems. Yet informal advocacy, especially in the context of the current dependence on paid forms of helping, needs to be nurtured and supported. This issue, along with other issues of advocacy *"development"*, needs to be considered as part of a definite strategy, particularly in relation to the nature and extent of government support.

5.5 The Need for Independent Advocacy

Independent advocacy, in essence, is advocacy which has the very minimum of conflicts of interest. By definition, independent advocacy cannot occur within, or in close connection with, formal human services. As mentioned previously, many activities which are carried out by formal human services are legitimate and useful activities and may even be utilised by advocacy efforts, but it is to the disadvantage of true advocacy for them to be confused with advocacy.

Clearly, independent advocacy may vary in terms of formality. Relatively formal advocacy models such as citizen advocacy, systemic and legal advocacy can operate with a high degree of independence as determined by minimal conflicts of interest. Relatively informal advocacy models such as personal advocacy provided by ordinary, interested people, can also operate with independence, although the presence of conflicts of interest may be somewhat more difficult to identify.

As a matter of principle, the authors support the proposition that all activities which are called advocacy must be measured against a rigorous criterion of independence and must be able to show that there is both consciousness of the presence of any significant conflict of interest, and efforts being made to minimise those that do exist. Accordingly, this issue is particularly relevant to the development of measures of advocacy *"quality"* such as may be part of any efforts to develop standards or methods of evaluating advocacy. In the establishment of new advocacy efforts, there should be a requirement that the maximum extent of independence and minimisation of conflicts of interest be a prerequisite.

5.6 The Vulnerability of Advocacy Itself

Advocacy is intrinsically vulnerable because of the necessity for advocacy efforts at times to stand in contradiction to formal services and systems, and some dominant cultural values and beliefs, in order to further the interests of people with disabilities.

The advocacy effort is vulnerable to both obvious and subtle undermining. A number of ways in which this might occur are described below (Breedlove 1979).

1. The advocacy organisation's appropriateness, legitimacy or capacity to engage in advocacy might be questioned.

2. The funding or other resources provided to the advocacy effort may be questioned in terms of its cost-effectiveness.

3. There may be an obsessive preoccupation with concrete outcomes rather than focussing on the need for advocacy and safeguards for people with disabilities.

4. Advocacy efforts may be called redundant, for example, because a human service says it has staff to carry out advocacy.

5. Everything might be called *"advocacy"* and result in a loss of focus and priority for true independent advocacy.

6. Advocacy efforts may be co-opted into the structure or control of formal systems and thus lose their independence and relevance to people with disabilities.

7. Advocacy efforts may be portrayed as *"over-idealistic"*, or *"out of touch with reality"* in focus, goals or practices.

8. There may be arguments to establish *"one-stop"* advocacy that will serve all purposes for everyone, possibly in the name of efficiency.

A key issue here is to acknowledge the need for legitimate accountability whilst ensuring that advocacy efforts are relevant, focussed and effective, without pursuing other purposes that are antagonistic to advocacy itself and the interests of people with disabilities.

5.7 Maintaining Relevance

Relevance refers to the extent to which advocacy efforts are directed towards and coherent with the real needs and interests of people with disabilities rather than, for example, following popular trends or the interests of other stakeholders. In addition, advocacy efforts should involve consciousness of their **manifest** as opposed to their **latent** functions. Manifest functions are those which are coherent with the stated functions of the advocacy effort and usually are ends-based. Latent functions are those which are inconsistent with stated functions and often drive organisations towards conflicting ends. For example, latent functions sometimes reflect processes and means. For example, attending meetings or responding to policy documentation may deflect advocacy efforts from the real intent which may be to achieve the integration of children with disabilities into education or the protection of adults who are being *"deinstitutionalised"*. A systemic advocacy organisation may have as its stated function to bring about systems change but its latent function is to appease powerful interests.

People engaged in advocacy efforts must be conscious of the distinction between placing energy into maintenance of organisational structures which are necessary to support the particular advocacy effort and treating organisational growth and development as the end in itself. Goal displacement is possibly the most common cause of programs losing their relevance.

The key influences on relevance are the processes utilised within the advocacy effort to identify the needs of the people for whom the advocacy is provided and the processes used to ensure that relevance, once achieved, is maintained. The advocacy effort is more likely to be relevant if advocates are clear about the assumptions they hold about the disadvantaged group and are *"grounded"* in knowledge of their needs and interests. These processes are sometimes grouped under the heading of *"renewal activities"*. They include activities which review

various aspects of the advocacy effort including purposes, principles, policies and practices and which are carried out periodically, in different ways, often with external involvement. Renewal essentially involves invigorating or reinvigorating commitment and ensuring that efforts remain coherent in their relevance to addressing needs, and vigorous in their expression.

5.8 Multi-Functional Advocacy Efforts and the Issue of Focus

Multi-functional advocacy refers to advocacy efforts which take a number of forms, for example:

- advocacy which operates both for individuals and systemically;

- advocacy which addresses the needs of multiple stakeholder groups such as families and people with disabilities;

- advocacy which addresses the needs of more than one group or class of people such as people with severe disabilities and people with mild disabilities.

This issue is concerned with the benefits and disadvantages of advocacy efforts which are multi-functional versus advocacy efforts which focus on a single function.

Multi-functional advocacy efforts may develop towards large size and the resultant formality and complexity. For some advocacy forms, for example those which focus on individuals, this may be a particular disadvantage. Smaller advocacy efforts are possibly more likely to be cohesive in their efforts and to have a more unified purpose. On the other hand, larger size may have some benefits in terms

of strength of influence and may be particularly appropriate for some forms of advocacy such as systemic advocacy.

Advocacy efforts which are very focussed are likely to develop greater understanding of the issues to be addressed and to develop more specialisation and effectiveness in terms of strategies and action.

If a number of functions are performed, the possibility of mutually antagonistic forces developing is increased (Wolfensberger 1992b). This refers to purposes that may not be consistent or coherent with one another, leading to internal confusion and reduced effectiveness within the advocacy body. For example, an advocacy effort which includes both individual and systemic advocacy will inevitably encounter situations where the broader interest conflicts with the individual interest, in much the same way as occurs in formal human services between the broader societal or organisational purposes and the well being of the individual. Other examples include a citizen advocacy organisation also taking on systemic advocacy, or a systemic legal advocacy effort taking on individual legal advocacy. Given the more immediate, pressing needs of individuals, it is highly likely that the more long-term systemic effort will lose priority and resources. In fact it will take great clarity, agreement and strength of purpose for systemic advocacy efforts to stay focussed.

On the other hand, advocacy efforts must be sufficiently grounded in direct contact and involvement with people with disabilities, to ensure focus and relevance. It may then be necessary to ground the advocacy effort in ways other than mixing systemic with individual advocacy. For example, the governance structure or a formal constituency group could contain a significant presence of people with disabilities.

Advocacy efforts which focus on more than one *"class"* of people such as families or parents and people with disabilities will encounter issues where the interests of the two groups do not correspond, lead-

ing to conflict and reduced effectiveness.

Providing advocacy to a wide range of groups needs very careful consideration. Advocacy which is more focussed on a particular group, for example people with physical disabilities, or people with severe intellectual disabilities, or people with disabilities who are institutionalised, is likely to be more *"expert"* and effective advocacy than advocacy which, for example, deals with *"all comers"*. There is also a very important issue of images transferring from one group to another to the detriment of both. For example, if the advocacy effort is for people who have a physical impairment and also people who have an intellectual disability, then each group could be perceived to have the additional impairment of the other. Inadvertently, such an advocacy effort may increase the personal vulnerability of people who are served.

A related issue is the extent to which the advocacy effort is focussed on an identified and delimited geographical area. Clearly, the wider the geographical focus, the more likely it is that confusions and conflicts will ensue. Some forms of advocacy such as systems advocacy are more likely to have a broader geographical focus whilst other forms such as individual advocacy are more likely to be effective within a more limited and identified context.

In examining these issues of focus, the conclusion is that generally speaking, the more focussed the advocacy effort, the more effective it is likely to be and the more likely it is that unnecessary conflict will be minimised. At the same time, it is also clear that the issue is complex and considerable thought should be given by prospective advocacy efforts in determining their focus. The most significant influence on decision-making in this area is the **purpose** of the advocacy effort. Thus it may make good sense for an effort which aims to provide systemic advocacy to take a national perspective. On the other hand, an individual, personal advocacy effort would soon become incoherent if its focus was national or even state/territory-wide.

5.9 Renewal and Accountability

Renewal and accountability are dealt with together here as separate, but related, concepts. Some measures which achieve renewal outcomes may also provide accountability and vice versa.

Renewal processes and activities have the aim of ensuring that the advocacy effort remains effectively focussed on its purposes and maintains energy and commitment. It also includes maintaining relevance in terms of the needs which are being addressed. Renewal addresses the natural tendency of all human activity to drift from its purpose over time and/or to be influenced by the range of pressures which lead to goal displacement. Given the multiplicity of interests within which advocacy operates and the difficult values issues in which it is immersed, renewal is of primary importance for advocacy organisations. Renewal is also concerned with the quality of the effort and particularly shares this aim with accountability measures. In fact, an advocacy effort which lacks focus and energy is also unlikely to be attaining any significant level of good quality.

Accountability is based on the assumption that advocacy efforts must be responsible for what they do. This responsibility takes different forms. For example, accountability addresses the extent to which an advocacy effort adheres to manifest or stated purposes; the extent to which it meets certain stated standards; the extent to which it achieves sufficient quality; and the extent to which the effort uses its resources appropriately. Each area of accountability requires somewhat different approaches.

The advocacy effort also has fundamental responsibility towards its stakeholders, particularly the primary constituent group. Accountability may thus be concerned with the structure and practices of the organisation which enable that responsibility to be met.

The following discussion on renewal and accountability is very brief and based in part on a number of sources. For readers wishing to address the relevant issues in more depth, there are many useful references by Wolfensberger and his colleagues (Wolfensberger 1977; Wolfensberger 1983a; Wolfensberger 1983b; Wolfensberger 1984).

Renewal and accountability processes and activities are considered here within three categories: internal measures; standards; and evaluation.

5.9.1 Internal measures for renewal and accountability

In his monograph on the development of voluntary associations, Wolfensberger detailed a number of measures that can be built into organisations which aim to maintain relevance, focus and energy and to strengthen the effort (Wolfensberger 1984). These measures could be seen as part of the normal consciousness and practices of an advocacy effort.

1.   **Maintaining membership activities, discontent with the status quo, and militancy vis-a-vis the service system.**

Wolfensberger stated that a major mechanism of renewal is the generation of a spirit of enthusiasm and militancy within the association. In this regard, renewal processes would ensure that there is a measure of dissatisfaction with the adequacy of the response to the needs of the person/people with disabilities and that the effort retained a strong concern with issues. Conversely, complacency and self-satisfaction would likely sap energy and commitment.

2. Nurturance of new and young members.

Advocacy organisations will be energised and *"kept on their toes"* by the injection of new membership which is allowed to question and challenge the existing order. This will also ensure that future leadership is planned for.

3. Meeting members' needs for affiliation and affection.

Wolfensberger (1984) identified the need for associations to provide their members with *"a sense of fellowship, belonging, mutual caring and affection"* as necessary in order to support member activity. To this end, advocacy efforts might promote appropriate member activities to ensure that the organisation does not become overly formalised and shut out members.

4. Creating ready avenues of personal involvement with the people who are the concerns of the effort.

In regard to advocacy, this renewal activity is possibly the most fundamental and important. Wolfensberger (1984) provided four reasons why it is vital that people engaged in advocacy-related activities should have ongoing intimate contact with members of the group of people with whom they are concerned.

(a) In representing a group or class, it is important that members never lose sight of individual experiences and fates. (b) Relatedly, people who make decisions for a class without having intimate contact with the people in that class tend to make perverse decisions. (c) Having occasion to spend time with people of the devalued group of concern may be one of the factors that motivates a person to join or remain in the (advocacy effort), especially if the person is not a human service worker or a relative of a handicapped individual. (d) Working towards a better world for

a class of devalued people can become a very abstract task — so much so that some members may no longer see the connection or relevance of the (advocacy) activity to its constituency and thus may begin to lose heart and interest.

(p. 32)

Wolfensberger then outlined a number of ways for ensuring more frequent and personal contact, including inclusion of people with disabilities in the organisation's activities, especially on the board and/or committees; arranging tours of service settings; and encouraging voluntary roles within service agencies.

5. Systematised and futuristic membership education.

Membership education is of the greatest importance in renewal, yet it is seldom organised systematically within advocacy efforts. Wolfensberger identified six elements of education.

a. Regular inclusion of educational content in general membership meetings, which should be held a number of times each year.

b. The creation of special need/interest groups which can pursue education and information.

c. Ensuring those engaged in the advocacy effort have knowledge of the subject matter of the area. In advocacy, this would include general knowledge about the nature, history and workings of the disability field; the nature and history of advocacy; the values and principles which underpin advocacy; and specialised knowledge about issues such as human service quality, safeguarding and monitoring of services.

d. Leadership training which might be more advanced and intensive for some people.

e.   Partnership programs of education or *"mentorship"* between experienced and inexperienced members.

f.   The holding of special educational events such as films/videos, group visits, workshops etc.

These internal renewal measures could be built into the ordinary planning of the activities of the advocacy effort.

5.9.2   Standards

The authors believe it is important for standards to be developed for advocacy efforts which reflect the particular nature of advocacy and its differences from formal human services. **This development should occur in a participatory process which ensures that people who are knowledgeable about advocacy and people who are engaged in advocacy are involved.**

There are a number of possible benefits from having standards relating to advocacy development and operation. Standards can:

1.   act as a resource for new or aspiring advocacy organisations and for others who are interested in advocacy;

2.   act as a basis for established advocacy efforts to retain focus and quality in their operations particularly through self-assessments;

3.   act as an exemplar and guide for how an ideal advocacy effort should operate;

4.   act as a basis for external evaluation activities which may be related to funding or other support.

The authors are aware of only one instrument for advocacy evaluation which incorporates standards. The **Standards for Citizen Advocacy Program Evaluation (CAPE)** was developed in the 1970s as a method for evaluating citizen advocacy programs and has been applied many hundreds of times in many countries (O'Brien undated). CAPE is currently being updated.

The standards in CAPE address three areas: adherence to citizen advocacy principles; citizen advocacy office effectiveness; and program continuity and stability. Each goal area has a heading or principle which is divided into a number of sub-areas for which there are standards and levels against which the performance of the advocacy agency can be evaluated.

The CAPE methodology reflects the extent of development of the citizen advocacy concept and its practice, and also an evaluation methodology which has been well tried and tested since the early 1970s in Normalisation and Social Role Valorisation evaluation methodology (Wolfensberger 1975; Wolfensberger 1983a). When used for external evaluation purposes, the evaluation team consists of at least three members. It is a requirement of the evaluation methodology that people involved in CAPE evaluations should have received previous training in the tool. In addition, team members should have some knowledge of advocacy. CAPE can also be used by an advocacy program for self-assessment and development purposes as a basis for program planning and design.

Whilst citizen advocacy programs can use CAPE for program planning, development and evaluation purposes, other forms of advocacy do not currently have standards. It is important that steps be taken to develop standards both for advocacy efforts generally, and possibly for specific forms of advocacy. This needs to be linked with a methodology for evaluation.

Standards should address at least the following six issues and areas of operation.

1. The core principles of advocacy.

These should be based on the principles outlined earlier in this monograph and would be reflected in both the policy documentation of the advocacy effort and in practices. The principles include:

- being on the side of the disadvantaged person/people;
- being concerned with genuine life needs;
- striving to minimise conflicts of interest;
- engaging in vigorous action;
- having fidelity to the people.

2. Specific principles for specific advocacy types.

It should be recognised that in addition to the set of core, higher order, universal principles in advocacy, there are specific principles which need to be developed and made explicit for different advocacy types, for example, for citizen advocacy, systemic advocacy and legal advocacy.

3. The structures which are utilised to provide advocacy.

Again, although different structures may be preferred for different advocacy purposes, higher order principles such as minimisation of conflicts of interest and fidelity to people with disabilities would shape standards.

4. The actual practices of the advocacy effort.

Standards would address a range of practices such as methods utilised to identify people for whom the advocacy is and is not provided; how advocacy is provided; the operations of governing bodies; matters concerning human resources etc.

5. Outcomes for the person/people

In the area of outcomes for people with disabilities, standards would reflect, amongst other things, the needs of people and the stated purposes of the advocacy effort.

6. Financial and other resource management issues

There is a range of issues around resource management for which standards are required.

5.9.3 Evaluation

There are a number of key rationales for the evaluation of advocacy efforts.

First, evaluation, particularly *"external"* evaluation, is a major means of influencing the quality and accountability of advocacy. There is an important assumption here that advocacy efforts should be accountable for the quality and effectiveness of what they do and that this accountability is to a number of stakeholders, including people with disabilities and, where appropriate, sources of funds.

Second, evaluation can serve as an activity which incorporates both a renewal purpose to maintain the focus of the advocacy, and an operationalisation of a set of standards. This assumes that it is possible to specify what constitutes quality in advocacy endeavours.

Third, the establishment of quality standards should incorporate a number of important principles, including:

- a principle of **comparability** by which it is possible to determine the extent to which an advocacy effort is achieving certain quality outcomes and the extent of further improvement or development which is needed;

- a principle of **optimality** whereby, rather than stating the standard in a minimal level that reflects the lowest common denominator of what is acceptable in the political sense, the standard reflects an ideal to which advocacy efforts would aspire;

- a principle of **communicability** to ensure that the quality standard is understood and can clearly be communicated amongst key stakeholders;

- principles of **universality** and **specificity** in which some standards reflect issues of quality which apply to **all** advocacy efforts, and other standards reflect specific advocacy types and situations.

Fourth, evaluation can be concerned with different dimensions of the advocacy effort. These dimensions were outlined above under the six areas that standards can address. It is important that the purposes of the evaluation in terms of the area/s addressed are clear to avoid the misapprehension that performance in one area, for example, efficient resource management, is the same as adherence to a set of core principles of advocacy or providing good quality outcomes for people with disabilities.

5.10 National and International Advocacy Networks

There are a number of possible benefits from the development of both national and international networks of advocacy efforts. Many advocacy organisations commented that they could see benefits in coming together to address particular issues. It was commented that to date there has not been a great sense of unity between advocacy organisations across Australia and very limited opportunity to develop mutual knowledge and understanding between the many different groups.

In her report on advocacy in South Australia, Cross (1992) identified a number of *"unnecessary constraints"* on advocacy efforts coming together in South Australia. These included:

1. competition between groups;

2. lack of communication between groups;

3. a sense of distrust;

4. a belief that some groups are trying to dominate or take over other groups;

5. a territorial focus;

6. devaluing of differences;

7. suspicion of anyone showing leadership;

8. historical issues as a barrier.

As commented by Cross (1992, p. 49), these restraints *"need to be challenged and overcome"*. Some of the benefits of a greater sense of unity and common purpose will be the strengthening of advocacy through such outcomes as:

1. developing a greater and clearer understanding of the various forms of advocacy which have been established within each state/territory;

2. learning from the approaches and strategies of different advocacy efforts as they address the range of advocacy issues;

3. sharing information on the foundations and structures of advocacy (such as the values base, theoretical and conceptual underpinnings);

4. identifying common problems/issues/concerns and their priorities;

5. advocacy efforts uniting around some common and important issues to strengthen the total effort;

6. providing moral support to one another.

This is an issue that needs to be addressed as part of strategies to promote and strengthen advocacy in Australia.

5.11　The Need for Advocacy Support Mechanisms

The development of high quality, effective advocacy efforts in Australia would be well-served by advocacy support mechanisms which could address a number of crucial developmental issues. Advocacy is in a relatively early stage of evolution in Australia. Although there is considerable *"practice wisdom"* which has developed over the past decade or so, there is little by way of literature or training, for example, which has emerged from local efforts with the possible exception of citizen advocacy. Similarly, policy development in advocacy is very under-developed and policy directions are unclear and confused. Advocacy support mechanisms would have the purposes of promoting advocacy efforts of high quality and effectiveness for people with disabilities in Australia and would support the development of local, national and international networks of advocacy efforts to increase the body of knowledge about advocacy.

The advocacy support mechanisms could incorporate the following functions.

1. Research and research and development activities which focussed on the nature of advocacy, the need for advocacy, the principles underpinning good quality advocacy efforts and the efficacy of different advocacy types and activities.

2. The development and provision of education and training for the full range of stakeholders in advocacy, including people with disabilities themselves, advocates, family members, citizens, and service providers.

3. The development of standards, quality measures and evaluation methodologies for advocacy.

4. The development and the provision of a bank of information on advocacy and the provision of a clearing house function.

5. Facilitating the publication and distribution of literature on advocacy.

6. Providing consultancy support to advocacy efforts which might include, for example, advice on the establishment of advocacy organisations and advising on or carrying out evaluations.

7. Auspicing focussed and public events/workshops/conferences on advocacy issues and the promotion of advocacy.

The nature of advocacy support mechanisms would need to address a number of difficult issues.

First, the purposes would encompass the full range of advocacy types which operate locally, at the state/territory and at national levels. Development at the state/territory and local levels will need to be facilitated and supported from a national mechanism. However, the purposes of such a national mechanism need to reflect the reality that the great majority of advocacy efforts, especially advocacy as defined in this monograph, occur at state/territory and local levels. There must be clear appreciation that there are issues in advocacy which need to be addressed at the national level and others that can only be addressed at the state/territory and local levels. This issue will be addressed further below.

Second, the mechanisms would need to have as much independence from human service providers as possible to reduce some conflicts of interest. The structures would need to have representation from some key stakeholder groups, primarily people with disabilities, people from advocacy groups and people who have specific experience and expertise relevant to advocacy development.

Third, such a mechanism would require government funding, preferably from both Commonwealth and states/territories, the latter being of particular importance for the fostering of more localised activities associated with advocacy development. The obvious problems here are the complexities involved in obtaining support from all governments, and the conflicts of interest involved if the government agencies which provide funding are involved in funding and/or providing human services to people with disabilities. These issues are addressed in more detail below in the broader context of the funding of advocacy.

5.12 The Funding of Advocacy

Across Australia, advocacy efforts are currently supported with funding by both Commonwealth and state/territory governments. The Commonwealth is the main funding body, providing 60 advocacy agencies with funds totalling $6.6m whilst state/territory governments provide funds to less than a third of these agencies (DACA Liaison Unit 1993).

The purposes of the Commonwealth and State Disability Agreement include enabling the two tiers of government to develop portfolios of human services responsibilities which do not overlap, thus reducing government administrative costs for service development and monitoring. The Commonwealth Government will take full responsibility for the funding and provision of employment services for people with disabilities and the state/territory governments will assume full responsibility for other service types. Both tiers of government will maintain joint responsibility for advocacy.

It has been stated and argued above that government, including both tiers, should maintain joint responsibility for supporting and

funding advocacy. The authors have noted with great concern that some areas of government are reducing their support for advocacy and even proposing to fund advocacy in ways that are likely to have dire consequences on advocacy development and ultimately on the well-being of people with disabilities. For example, the *"one-stop-shop"* advocacy supermarket will lead to a travesty of most of the principles of advocacy detailed in this monograph. Relatedly, the heavy reliance on costly formal protective services which have become a feature of modern human service systems needs critical examination. Policies grounded in economic rationalism and pragmatism, although seemingly impelling in the existing culture of values, are in danger of further disempowering and disengaging ordinary people and in the medium term at least, will be seen to be counterproductive.

In addition to government funding, advocacy efforts rely heavily on in-kind support from their allies and supporters. This includes, for example, board members' voluntary contributions, employees of advocacy agencies who commonly provide more than their allotted time out of their personal commitments and, of course, advocates themselves who often expend considerable personal resources in their support of people with disabilities. Frequently, advocacy agencies receive various forms of support from local citizens and community groups and are often well placed to mobilise this support. It would be an interesting and illuminating task to determine the proportion of total resources utilised by advocacy efforts which is comprised of informal resources compared with government funds. It is a plausible hypothesis that advocacy, as a form of people helping people, is resource efficient.

The authors have noted that advocacy attracts people who are highly intrinsically motivated towards advocacy for people with disabilities and are also willing to invest their selves and their own resources in this process. For example, it is commonplace for people involved in advocacy efforts to use their own vehicles, cash and time in related activities.

In terms both of purpose and efficiency, it is clearly advantageous for advocacy agencies to continue to attract both financial and in-kind support from their communities. In addition to minimising those conflicts of interest associated with government funding of advocacy, advocacy movements which are well-supported by their communities can be more independent of, and better able, if necessary, to take issue with government. Such community support provides justification to the claim that advocacy is embedded within and part of the community. Advocacy efforts may attain more security with a broad rather than a narrow base of financial and other support.

Many advocacy agencies conduct fund-raising activities and some agencies would not be able to maintain their efforts without such income. Although fund-raising may be vital to the survival of some advocacy agencies, the form and nature of fund-raising has the potential to impact negatively on the image of people with disabilities and possibly undermine the other activities of the agency which are designed to promote the dignity and value of people with disabilities. There needs to be high consciousness and careful consideration of such activities in all human services and especially in advocacy efforts which assume a particular stance on behalf of people with disabilities.

Because of conflicts of interest associated with responsibilities for funding and providing formal services for people with disabilities, it has been argued that government funding for advocacy should be administered by departments which are not so compromised. For example, Commonwealth and state/territory departments concerned with the administration of justice, equal opportunity or human rights have been suggested as more appropriate to fund advocacy. This position is supported by the possibility that conflicts of interest will be lessened, although since funds are still coming from government, not entirely eradicated.

On the other hand, there is considerable concern that alternative government departments may have little or no interest in, commitment to and/or understanding of advocacy for people with disabilities. This will inevitably lead to a lowered priority within government for advocacy and possibly ultimately result in little or no support. In addition, no matter where the funding is administered within government, the advocacy movement will be vulnerable to the influence of the ideological and functional perspectives of that funding body. For example, whilst the Disability Services Program may have a formal service perspective, a justice-related department will have a legalistic perspective.

A common, but by no means consensual view amongst people concerned with advocacy, is that although there are clear conflicts associated with disability-related government departments funding advocacy, at the least these departments have demonstrated some interest, understanding and commitment to advocacy. Particularly since the Disability Service Act 1986, there has been some understanding of the nature and purposes of advocacy at the Commonwealth level, and some state/territory disability-related departments have also provided limited support to advocacy. This argument leads to the most conservative position that was described by one commentator's wry observation that *"it's better the devil you know than the one you don't"*.

It is the view of the authors of this monograph that in the present overall context, responsibility for the funding and support of advocacy for people with disabilities should remain with the Commonwealth and state/territory government departments which have responsibility for services for people with disabilities with some additional mechanisms designed to minimise conflicts of interest and ensure that the purposes and nature of advocacy are respected. These mechanisms are described below where the roles of government in advocacy are considered.

5.13 The Role of Governments in Advocacy

It must be acknowledged that advocacy development for people with disabilities in Australia is relatively new. Most development has occurred in the 1980s with particular enhancement by the Commonwealth Disability Services Act in the mid-1980s. This is an area where policy development and practices are still evolving and are not yet particularly clear or sophisticated. Given the nature and purposes of advocacy, the role of governments in advocacy development is especially unclear and the subject of considerable discussion and uncertainty. Consequently, the address of this issue should be seen as developmental and as providing direction, rather than being definitive or detailed. In fact we believe it is important that policy development and planning in advocacy development should occur within a framework of different time scales. **It is the authors' view that there is a pressing need for more detailed policy development to occur and, given the nature and purposes of advocacy, this process must be participatory with the agenda largely set by people with disabilities and their allies and advocates and incorporating an initial time perspective of 5-10 years.**

This complex issue is addressed here under three headings: Rationales for government involvement in advocacy; Principles for government involvement in advocacy; and Structures.

5.13.1 Rationales for government involvement in advocacy

The authors hold a basic assumption that it is essential that government involvement in advocacy development continues and, in fact, be increased. There are at least three strong rationales for government involvement in advocacy for people with disabilities in Australia.

First, the doctrine of *parens patriae* has clearly established an historical precedent and moral imperative for state involvement in and responsibility for protecting the rights and integrity of people who are vulnerable in society, including people with disabilities. In modern parlance, this is represented by statements of social justice and individual rights. By and large, each Australian government has acknowledged these in one way or another through becoming signatories to international covenants, by legislation, by the adoption of formal policies, and the establishment of a large number of statutory and less formal bodies which have the purpose of pursuing social justice ends. **In this regard, it is important to note that the responsibility of the state goes beyond its political and bureaucratic roles as mediator between different interest groups.** There is a common expectation in enlightened democracies that governments should take a particular interest in those who are vulnerable or lacking in power and influence and should be prepared to provide positive discrimination in their favour. Advocacy provides an important means by which governments can pursue social justice ends.

Second, the state has a primary interest in and responsibility for the development of a culture of participation and involvement by ordinary citizens. If people are disinterested or uninvolved this does not detract from, but rather strengthens, the importance of this rationale. Any measures which reduce the capacity of ordinary people and communities to be self-reliant and to represent their own interests, are counterproductive according to this rationale. **Governments should in principle support measures which facilitate the capacity and actions of citizens to be involved in their communities, to represent their own interests, and to participate in the building of communities which are characterised by the inclusion of all citizens.** In this regard, governments appropriate monies from their citizens, through various forms of impost, some of which reasonably should be returned to the citizenry to promote and build community and participation. It is an unfortunate observation of modern life that ordinary citizens are struggling to maintain a measure of dignity and

self reliance, and many elements of our post-technological society are noted more for their destructive influences on communities than for their community building. **Unlike formal human service systems, advocacy provides a means by which ordinary citizens can participate and become involved in processes which are essentially community building and empowering and which foster characteristics of compassion and caring for fellow citizens.**

Third, governments over many generations have been the major influence on the development of formal human service systems, with both their benefits and imperfections. This establishes a primary responsibility on the part of governments to support advocacy development as a means of countering many of the harmful outcomes which occur when vulnerable people are embedded within formal systems. The nature of this responsibility is twofold. **First, it is a moral responsibility** in the sense that governments have been the major architects of the formal system. Second, the responsibility is functional in the sense that the full stated objectives of government for vulnerable people cannot be achieved by formal systems (if at all) without the checks and balances of independent advocacy. This rationale also provides a caution that advocacy itself is vulnerable to taking on the very characteristics of formal human services which it is intended to challenge if the manner in which it is supported by governments does not take this risk into account.

5.13.2 Principles for government involvement in advocacy

A number of principles which should influence the nature of government involvement are consistent with the concept of advocacy which has been developed through this monograph.

1. Governments should view advocacy as a fundamental and

essential safeguard for people with disabilities who are vulnerable or socially devalued and not as something secondary to formal human service development, or beyond the responsibility of government.

2. The role of governments should emphasise the **maintenance and development** of advocacy, not its control. In this regard, it is important that advocacy be recognised and supported in its *"differentness"* from human services. The nature of accountability sought by governments which provide public resources to advocacy efforts must reflect the different purposes and nature of advocacy and the primary accountability of advocacy efforts **to people with disabilities.**

3. Governments will legitimately provide and support a variety of protective measures and these should not be confused with advocacy, but rather be seen as measures which may be utilised by advocates. Similarly, governments may legitimately support certain representative bodies such as peak organisations from which governments may seek advice and support, but this also should not be confused with advocacy.

4. Expenditure of resources by governments on advocacy should be proportional to four factors and policies should explicitly reflect this principle. These factors are recognisable as well-known principles of risk insurance in which the size of the risk determines the extent of the safeguard and underwriting:

   a) the greater the investment of governments in formal systems of human services, the greater should be governments' investment in advocacy — expenditure of resources on advocacy should be proportional to expenditure of resources on formal services;

   b) the greater the extent of social turbulence and dislocation, the greater should be governments' investment in advocacy;

   c) the greater the development of internal protective measures, that is, measures which are administered by either the service systems themselves or by service funding agencies, the greater should be governments' investment in *"external"* and *"independent"* advocacy;

   d) because advocacy is at a relatively early stage of development, government investment in advocacy needs to be greater than it would otherwise be.

   The proportion of total government outlays in human services which are devoted to advocacy should be clearly stated to enable discussion and negotiations to occur.

5. To minimise conflicts of interest and to reflect the nature of advocacy, dispersal of resources by governments to advocacy should be as independent as possible from government agencies which have a responsibility for either providing directly, or funding the provision of, human services to people with disabilities.

6. In order to promote the participation of citizens and the community and to enhance the independence of advocacy, government support of advocacy should be complemented where appropriate by acknowledged community contributions which may include in-kind support, the time of citizens and financial resources.

7. A primary role of governments in advocacy is to provide support and resource structures which develop and promote advocacy.

8. Structurally, advocacy efforts should be encouraged to be developed as locally as possible, depending on the advocacy type. To this end, there should be a particular focus on advocacy development at state/territory and local levels with the role of government being to provide financial and technical support to enable this to happen.

9. Government support for advocacy should be influenced to the greatest possible extent by ordinary citizens and people with disabilities themselves.

5.13.3   Structures

The respective roles of the Commonwealth and state/territory governments should be clearly spelled out. There are a number of factors which should be taken into account in this process.

Governments' roles should reflect the emergence of the Commonwealth-State Disability Agreement and the consequent state/territory legislation and the acknowledgment that advocacy will remain a responsibility of **both levels of government.** In the view of the authors, this is entirely appropriate although the roles of both levels of government may differ.

The vital role the Commonwealth has played both in the development of explicit principles for human service development and in the support of advocacy in the Disability Services Act needs to be acknowledged. The Commonwealth's developmental role has been and will continue to be of great importance. This is especially because the relative independence of the Commonwealth from direct service provision and its national focus and responsibilities have facilitated its involvement in issues of principle and advocacy in human services. **In the development of effective structures for advocacy, it is vital**

that the Commonwealth sustains a major role and takes the leadership, if necessary, to ensure that appropriate mechanisms are established at both the state/territory and national levels. The authors are of the view that if the Commonwealth resiles from this leadership role, advocacy in Australia will be significantly weakened and setback.

Advocacy development needs technical support to address issues associated with research and development, promotion, training, leadership development etc. To be effective, this needs to be supported at the national level and delivered at the state/territory and local levels. At the same time, there are crucial issues that effect advocacy nationally and can only be effectively addressed by a national mechanism. For example, an obvious national issue involves the determination of Commonwealth funding priorities for advocacy. Although such decisions are made at a national level, they must be well informed from the state/territory and local levels.

Three sets of purposes can be described which translate into three mechanisms, two at the state/territory level and one at the national level.

At the state/territory level, the **first** set of purposes is concerned with **resource allocation and some elements of accountability** including:

- deciding local priorities for advocacy;

- deciding which advocacy efforts should be supported and to what extent support should be given;

- dispensing government resources to advocacy;

- determining accountability for the quality of the advocacy effort and the utilisation of resources.

A mechanism to carry out these purposes essentially would consist of representatives from the funding bodies and from the advocacy movement with additional involvement from citizens and people with specific relevant expertise.

The **second** set of purposes at the state/territory level is concerned with **providing and facilitating resources and technical support for advocacy efforts** through:

* encouraging the development of high quality advocacy efforts particularly at the local level;

* research and development activities;

* provision of education and training;

* developing standards, quality measures and evaluation methodologies;

* providing information, clearing house functions and support to the development of local, state/territory, national and international networks;

* developing and disseminating literature on advocacy;

* providing and facilitating the provision of consultancy support to advocacy efforts;

* providing public events to highlight aspects of advocacy.

A mechanism to carry out these purposes would consist of people with specialist knowledge of advocacy and related issues. Such mechanisms could possibly be located within tertiary institutions. No direct advocacy would be carried out by this mechanism.

Two **separate** mechanisms at the state/territory level are suggested. Although there are clear advantages in these two purposes being linked, it is suggested that decisions about resource allocation should be **informed by,** but not confused with or conflicted with, the provision of technical support to advocacy development. There may be some common membership associated with each purpose.

The **third** set of purposes is at the national level and is concerned with **issues of national focus.** Such purposes include:

* the establishment and coordination of national priorities and plans for advocacy development in Australia and the oversight of the implementation of those activities;

* the address of advocacy issues which are of national focus — for example, the development of standards, outcome measures and evaluation methodologies;

* supporting the development of effective advocacy at the state/ territory and local levels;

* recommending to the appropriate Commonwealth Minister on the expenditure of funds for both advocacy efforts and advocacy research and development activities;

* providing a national auspice for national meetings/workshops/ conferences on advocacy and for the state mechanisms to meet;

* providing a national clearing house function.

Although under the auspice of the Department of Health, Housing, Local Government and Community Services, the national advocacy mechanism should operate with as much independence as possible from the sections of the Department which are concerned with

the funding of formal services for people with disabilities. The national mechanism could consist of a small secretariat and representatives from each of the two suggested state advocacy mechanisms with the support of other persons who may have expertise required to address specific national tasks or priorities. The national mechanism would not provide any direct advocacy. Its development functions could be contracted out to state/territory groups or other bodies with the required expertise.

6.0 Recommendations

6.1 Definition

A definition of advocacy which includes the following aspects should be considered for adoption by people concerned with advocacy for people with disabilities.

Advocacy refers to functioning (speaking, acting, writing) with minimum conflict of interest on behalf of the sincerely perceived interests of a person or group, in order to promote, protect and defend the welfare of, and justice for, either individuals or groups, in a fashion which strives to be emphatic and vigorous.

6.2 Principles

The following principles should be considered for adoption by people concerned with advocacy for people with disabilities and should underpin policy development and the practice of advocacy.

1.   Advocacy is on the side of the disadvantaged person/people.

2.   Advocacy is concerned with genuine life needs.

3.   Advocacy strives to minimise conflicts of interest.

4.   Advocacy engages in vigorous action.

5.   Advocacy has fidelity to disadvantaged people.

6.3 Policy Development

6.3.1 Need for a developmental perspective

It should be acknowledged by those concerned with advocacy that advocacy for people with disabilities in Australia is in the early stages of development and policy and practice reflect this. There are many issues of policy and practice in advocacy which are unclear and confused making it necessary both to invest resources into advocacy development and to anticipate that some time will elapse before many difficult issues are clarified.

6.3.2 Distinctiveness of advocacy

Advocacy represents a distinctive response to the vulnerability of people with disabilities that is very different from the response of formal human services and formal protective services. Advocacy differs in its purposes, values, underpinning principles, vision and its connection with a social movement. These differences must be acknowledged and reflected in education, policy and practice in advocacy in order to minimise confusions and strengthen the effectiveness of advocacy.

6.3.3 Informal advocacy

In terms of policy development and priority setting for resourcing and developing advocacy, informal advocacy should receive particular attention and priority because it represents the most normative and expectable response to vulnerability and because it can address needs that more formal responses cannot address.

6.3.4 Independent advocacy

In terms of policy development and priority setting for resourcing and developing advocacy, independent advocacy should receive particular attention and priority because of its potential to address the needs of vulnerable people more effectively than some other advocacy forms.

6.3.5 Standards

The development of standards for high quality advocacy is a priority for policy and practice. Standards must reflect the distinctiveness of advocacy compared with formal human services and protective services and should address at least the following six issues.

1. **The core principles of advocacy.**
2. **Specific principles for specific advocacy types.**
3. **The structures which are utilised to provide advocacy.**
4. **The actual practices of the advocacy effort.**
5. **Outcomes for the person/people.**
6. **Financial and other resource management issues.**

6.3.6 Evaluation

All advocacy efforts should engage in regular external evaluation and related renewal processes to assist in maintaining accountability and to ensure that high levels of focus and coherency are achieved. A major priority for advocacy policy and practice is the development of evaluation standards and methodologies. These

should reflect a number of principles including **comparability, optimality, communicability, universality and specificity.**

6.3.7   Priorities

Advocacy development must be concerned with addressing the needs of people who are extremely vulnerable and/or devalued. Such groups commonly include people with multiple disadvantages, people who are or have been in the care of formal services for a long period of time (often in large institutions), people from particular racial and ethnic groups, people from remote and rural communities and people with very severe impairments. Further research, policy development and advocacy support is a very high priority for these people.

6.4 The Roles of Governments in Advocacy

6.4.1   The nature of government responsibility

It must be acknowledged in policy development, support for, and practice in advocacy that all governments have a deep responsibility to promote independent advocacy because of:

- historical precedent and the associated moral imperative regarding government concern for vulnerable people;

- the need for governments of *"enlightened"* democracies to foster a culture of participation and involvement by ordinary citizens and the development of a society which is characterised by the inclusion of all citizens;

- the need to balance the fact that government is the prime architect and supporter of formal responses to vulnerability through the human service system and protective services.

6.4.2   The leadership role of the Commonwealth Government

Because of its historical support for advocacy development, its indirect role in service provision, its funding capacity and its national perspective, it is imperative for the ongoing development of advocacy in Australia that the Commonwealth Government's role is acknowledged. It is strongly recommended that the Commonwealth's leadership role and commitment to advocacy in Australia is maintained and strengthened.

6.4.3   The nature of government support

Government support to advocacy should ensure that advocacy efforts are developed and maintained and must avoid exerting control or co-opting advocacy to serve bureaucratic or political ends. Most importantly, governments have a responsibility to be clear about the distinctiveness of advocacy from other activities which may be useful and legitimate since the governments' mistaken response in this issue can serve to undermine and weaken advocacy.

6.4.4   Government resourcing of advocacy

Expenditure of resources by government on independent advocacy should be proportional to their investment in formal human service responses, including *"internal protective measures"* which are controlled by formal systems, and should also reflect the extent of

social turbulence which exacerbates vulnerability. In addition, government investment in advocacy must recognise its developmental needs.

6.4.5   Proportional government funding

The proportion of total government outlays in human services which are devoted to advocacy should be clearly stated to enable discussion and negotiation to occur.

6.4.6   Conflicts of interest

In their support for advocacy, governments should minimise conflicts of interest, particularly those which are concerned with their role in the funding and support of formal human services. This can be done by a number of means including separating out the mechanisms for advocacy support from departments or sections of departments which fund formal services and ensuring that there is effective consultation with and participation by the primary stakeholders in advocacy.

6.5 Support Structures for Advocacy Development

The most pressing need for advocacy development in Australia is the provision of a framework or structure for advocacy at the Commonwealth and state/territory levels which can acknowledge the distinctiveness of advocacy and effectively address critical developmental issues. Three mechanisms are recommended and described in **Section 5.13.3**. These mechanisms are outlined as follows.

6.5.1   State/Territory resource allocation and accountability mechanism

It is recommended that a mechanism is established within each state/territory by each state/territory and the Commonwealth Governments to identify local priorities, allocate resources and ensure appropriate accountability for advocacy efforts.

6.5.2   State/Territory resource and technical support mechanism

It is recommended that a mechanism is established within each state/territory by each state/territory and the Commonwealth Governments to provide a range of resources and technical support to local advocacy efforts.

6.5.3   National priority-setting and resource mechanism

It is recommended that the Commonwealth Government establish a national mechanism with the purpose of addressing national advocacy issues and recommending to the appropriate Minister on the priorities and funding of advocacy.

7.0 Bibliography

Acton, J. and Lamond, A. (1972). **Ralph Nader: A man and a movement.** New York.

American Association of Homes for the Aging. (1984). **The continuing care retirement community (revised edition).** Washington, D.C.: American Association of Homes for the Aging.

Beilhartz, P., Considine, M., and Watts, R. (1992). **Arguing about the welfare state.** North Sydney: Allen & Unwin.

Bell, D. (1973). **The coming of post-industrial society. A venture in social forecasting.** New York: Basic Books, Inc. Publishers.

Breedlove, L. (1979). **The vulnerability of advocacy.** Unpublished work.

Burgdorf, R. L. (1980). **The legal rights of handicapped persons. Cases, materials, and text.** Baltimore: Paul H. Brookes.

Callahan, J. J. (1988). Elder abuse programming: Will it help the elderly? **The Urban & Social Change Review, 3** (1-v), 15-16.

Cockram, J., Jackson, R. and Underwood, R. (1992). Perceptions of the judiciary and intellectual disability. **Australian and New Zealand Journal of Developmental Disabilities.** (in press).

Cocks, E. (1987). Human services for people with intellectual disabilities in an era of turbulence and "altered consciousness". **Australian and New Zealand Journal of Developmental Disabilities, 13** (3), 133-140.

Cocks, E. (1989). **An introduction to intellectual disability in Australia (Second ed.).** Canberra: Australian Institute on Intellectual Disability.

Cocks, E. (1990). **Review of the W.A. Authority for Intellectually Handicapped Persons Act 1985.** Centre for the Development of Human Resources, Edith Cowan University.

Cocks, E. (1992). **Encouraging a paradigm shift in services for people with learning disabilities.** Keynote Address at the British Institute for Mental Handicap Annual Conference, Heriot Watt University, Edinburgh.

Commonwealth Department of Community Services and Health (undated). **I know what's right for me. Caring for older Australians.** Canberra: Australian Government Publishing Service.

Commonwealth Department of Community Services and Health (undated). **The residential care program for aged people.** Canberra: Pirie Printers Sales Pty Ltd.

Cross, J. (1992). **An examination of disability related advocacy in South Australia.**

Crystal, S. (1987). Elder abuse: The latest "crisis". **The Public Interest, 88** (Summer), 56-66.

Dalley, G. (1988). **Ideologies of caring. Rethinking community and collectivity.** Basingstoke: MacMillan Education.

Department of Health, Housing, Local Government and Community Services, (1986). **Advocacy services.** Canberra: Australian Government Publishing Service.

Deveson, A. (1978). **Australians at risk.** Melbourne: Cassell.

Diessenbacher, H. (1989). Neglect, abuse and taking of life in old people's homes. **Ageing and Society, 9,** 61-71.

Edgar, D. (1992). Changing families, changing societies. **Family Matters, 32** (April).

Elvik, S. L., Berkowitz, C. D., Nicholas, E., Lipman, J. L., and Inkelis, S. H. (1990). Sexual abuse in the developmentally disabled: Dilemmas of diagnosis. **Child Abuse & Neglect, 14,** 497-502.

Ferguson, E. (1978). **Protecting the vulnerable adult: A perspective on policy and program issues in adult protective services.** Ann Arbor: Institute of Gerontology.

Finch, J. (1989). **Family obligations and social change.** Cambridge: Polity Press.

Fitzgerald, D. (1982). Mental health — Violence and natural justice. **Mental Health in Australia,** (December), 4-9.

Freeman, J. (1983). **Social movements of the sixties and seventies.** New York: Langman.

Gallagher, H. G. (1990). **By trust betrayed. Patients, physicians and the license to kill in the Third Reich.** New York: Henry Holt and Company.

Gaylin, W. (1981). In the beginning: Helpless and dependent. In W. Gaylin, I. Glasser, S. Marcus and D. Rothman (Eds), **Doing good: The limits of benevolence** (pp. 1-38). New York: Pantheon Books.

Gaylin, W., Glasser, I., Marcus, S., and Rothman, D. (1981). **Doing good: The limits of benevolence.** New York: Pantheon Books.

Glasser, I. (1981). Prisoners of benevolence: Power versus liberty in the welfare state. In W. Gaylin, I. Glasser, S. Marcus and D. Rothman (Eds), **Doing good: The limits of benevolence** (pp. 97-170). New York: Pantheon Books.

Graycar, A. (1983). **Retreat from the welfare state.** Sydney: Allen and Unwin.

Green, M. J. (1973). **The monopoly makers: Ralph Nader's study group on regulation and competition.** New York.

Habermas, J. (1989). **The new conservatism. Cultural criticism and the historians' debate.** Cambridge: Polity Press.

Hickson, L. (1991). **Uncovering a hidden tragedy. Elder abuse.** Australian Women's Weekly, March, 67-71.

Illich, I. (1977). **Disabling professions.** London: Marion Boyars.

Jezewski, T. (undated). **Not common knowledge. Self help groups.** Perth: Western Institute of Self Help.

Johnson, K., Andrew, R. and Topp, V. (1988). **Silent victims: A study of people with intellectual disabilities as victims of crime.** Melbourne: Office of the Public Advocate.

Kittrie, N. (1971). **The right to be different: Deviancy and enforced therapy.** Baltimore: Johns Hopkins Press.

Lagergren, M. (1985). Public health care services in the advanced welfare state. **Futures,** (August), 348-359.

Madigan, J. (1992). **Qualitative research methods.** Lecture at Edith Cowan University, May, Perth.

Marcus, S. (1981). Their brothers' keepers: An episode from English history. In W. Gaylin, I. Glasser, S. Marcus and D. Rothman (Eds), **Doing good: The limits of benevolence** (pp. 29-66). New York: Pantheon Books.

Marshall, E. (1971). St Nader and his evangelists. **The New Republic,** (October).

Maslow, A. H. (1943). A theory of human motivation. **Psychological Review, 50,** 370-396.

Mason, J. (1984). Abuse and neglect of children and disabled adults: North Carolina's mandatory reporting laws. **Popular Government, 48** (4), 1-9.

McKnight, J. (1976). The professional service business. **Social Policy, 8** (3), 110-116.

McKnight, J. (1986). Social services and the poor: Who needs who? **Utne Reader,** (Feb-Mar), 118-121.

McKnight, J. (1988). Regenerating community. **Interaction, 2** (5), 7-13.

McKnight, J. (1989a). **Do no harm: A policymaker's guide to evaluating human services and their alternatives.** Northwestern University: Centre for Urban Affairs and Policy Research.

McKnight, J. (1989b). Why "servanthood" is bad. **Interaction, 3** (1), 27-31.

Meyere, C. de and Jezewski, T. (1985). **Helping hand: A guide for self help groups.** Perth: Western Institute of Self Help.

Michael, D. N. (1983). Competence and compassion in an age of uncertainty. **World Future Society Bulletin,** (Jan/Feb), 1-6.

Mishra, R. (1984). **The welfare state in crisis: Social thought and social change.** Brighton: Wheatsheaf Books.

Morgan, S. R. (1987). **Abuse and neglect of handicapped children.** Boston: College-Hill/Little, Brown.

Morris, R. (1990). The evolution of a social concern base for policy about vulnerable populations. In Z. Havel, P. Ehrlich, and R. Hubbard (Ed.), **The vulnerable aged** (pp. 208-222). New York: Springer Publishing.

Mullins, J. B. (1986). The relationship between child abuse and handicapping conditions. **Journal of School Health, 56** (4), 134-136.

New South Wales Law Reform Commission. (1992). **People with an intellectual disability and the criminal justice system.** NSW Law Reform Commission.

Nirje, B. (1985). The basis and logic of the normalisation principle. **Australian and New Zealand Journal of Developmental Disabilities, 11** (2), 65-68.

OECD. (1981). **The welfare state in crisis.** Geneva: Organisation for Economic Cooperation and Development.

Paluski, J. (1991). **Social movements: The politics of moral protest.** Melbourne: Longman Cheshire.

Parker, G. (1991). Developmentally disabled, doubly disadvantaged. **The Medical Journal of Australia, 155** (July 15).

Perske, R. (1981). **Hope for the families. New directions for parents of persons with retardation or other disabilities.** Nashville: Abingdon Press.

Resnick, H. (1992). **Analysing organisations.** Lecture presented to Master of Social Science students at Edith Cowan University, Western Australia.

Rosen, M., Clark, G. R., and Kivitz, M. (1977). **The history of mental retardation.** Baltimore: University Park Press.

Rothman, D. J. (1981). The state as parent: social policy in the progressive era. In W. Gaylin, I. Glasser, S. Marcus and D. Rothman (Eds), **Doing good: The limits of benevolence** (pp. 67-96). New York: Pantheon Books.

Scheerenberger, R. C. (1987). **A history of mental retardation.** Baltimore: Paul H. Brookes Publishing Co.

Schwartz, D. B. (1992). **Crossing the river: Creating a conceptual revolution in community and disability.** Pennsylvania: Brookline Books.

Szasz, T. (1974). **Law, liberty, and psychiatry: An inquiry into the social uses of mental health practices.** New York: MacMillan.

Tharinger, D., Horton, C. B., and Millea, S. (1990). Sexual abuse and exploitation of children and adults with mental retardation and other handicaps. **Child Abuse & Neglect, 14,** 301-312.

Toffler, A. (1980). **The third wave.** New York: William Morrow and London.

Toffler, A. (1990). **Power shift: Knowledge, wealth, and violence at the edge of the 21st century.** New York: Bantam Books.

Turnbull, H. R. (1981). **The least restrictive alternative: Principles and practices.** Washington, DC: American Association on Mental Deficiency.

Verick, M. (1991). **Medication used to control people in state government institutions.** Canberra: National Council on Intellectual Disability.

Volker, D. (1987). Administration in the welfare state. **Canberra Bulletin of Public Administration, 51** (May), 82-86.

Walker, A. (1987). Enlarging the caring capacity of the community: Informal support networks and the welfare state. **International Journal of Health Services, 17** (3), 369-386.

Weicker, L. (1987). The Protection and Advocacy for Mentally Ill Individuals Act. **American Psychologist, 42** (11), 1027-1028.

Williams, T. A. (1982). **Learning to manage our future. The participative redesign of societies in turbulent transition.** New York: John Wiley and Sons.

Wolfensberger, W. (1972). **The principle of normalization in human services.** Toronto: National Institute on Mental Retardation.

Wolfensberger, W. (1973). Citizen advocacy for the handicapped, impaired and disadvantaged: An overview. In W. Wolfensberger, & H. Zauha (Ed.), **Citizen advocacy and protective services for the impaired and handicapped** (pp. 7-20). Toronto: National Institute on Mental Retardation.

Wolfensberger, W. (1975). **The origin and nature of our institutional models.** Syracuse: Human Policy Press.

Wolfensberger, W. (1977). **A balanced multi-component advocacy/**

protection schema. Ontario: Canadian Association for the Mentally Retarded.

Wolfensberger, W. (1983a). **Reflections on the status of citizen advocacy.** Toronto: National Institute on Mental Retardation.

Wolfensberger, W. (1983b). Social role valorization: A proposed new term for the principle of normalization. **Mental Retardation, 21** (6), 234-239.

Wolfensberger, W. (1987). **The new genocide of handicapped and afflicted people.** Syracuse University: Training Institute for Human Service Planning, Leadership and Change Agentry.

Wolfensberger, W. (1987a). Values in the funding of social services. **American Journal of Mental Deficiency, 92,** 141-143.

Wolfensberger, W. (1989). Human service policies: The rhetoric versus the reality. In L. Barton (Ed.), **Disability and dependency,** (pp. 23-41). London: Falmer Press.

Wolfensberger, W. (1992a). **A brief introduction to social role valorization as a high-order concept for structuring human services (Second ed.).** Syracuse: Training Institute for Human Service Planning, Leadership and Change Agentry.

Wolfensberger, W. (1992b). **Social advocacies on behalf of devalued and disadvantaged people.** Workshop provided at Adelaide.

Wolfensberger, W., and Zauha, H. (1973). **Citizen advocacy and protective services for the impaired and handicapped.** Toronto: National Institute on Mental Retardation.

World Health Organisation. (1980). **Classification of impairments disabilities and handicaps.** Geneva: World Health Organisation.

8.0   Appendices

8.1 Appendix A: Professor Wolfensberger's Australian visit, 1992 — Description of events

This description is provided as indicative of the material which has been developed by Professor Wolfensberger related to advocacy and provided in training events. The information is derived from descriptions of each training event which were provided by the event organisers. The events were held in Adelaide in September, 1992 and were very well attended by people from all over Australia and from New Zealand.

Event 1
A 5 day Seminar
SOCIAL ADVOCACIES ON BEHALF OF DEVALUED AND DISADVANTAGED PEOPLE

This event defined and explained different kinds of advocacy on behalf of disadvantaged and oppressed people, the reasons why advocacy is particularly needed today, the principles of effective advocacy, the threats to it, and the safeguards that need to be built into its practice.

It also examined what advocacy is, why social advocacies on behalf of devalued people are always needed, forms of advocacy (e.g. agency advocacy, individual and collective advocacy etc.), the strengths and limitations of the various advocacy forms, ways of conceptualising and clarifying them, the issue of conflict of interest, and the essential elements that should be present in any form of advocacy in addition to freedom from conflict of interest.

Event 2
1 day
AUSTRALIA-SPECIFIC SOCIAL ADVOCACIES EVENT

This event involved presentations by local presenters of specific Australian social advocacy, protection or guardianship schemes, whether currently operational or proposed, along with an analysis and critique led by Dr Wolfensberger.

Event 3
2 days
CITIZEN ADVOCACY

Citizen advocacy is a one-to-one, voluntary (unpaid) relationship between a competent, valued citizen and an impaired or devalued person, in which the competent citizen *("advocate")* undertakes to represent the needs of the impaired person *("protege")* as if they were the advocate's own.

This event involved an elaboration of the essential components that must be built into, and safeguarded in, a citizen advocacy program. Some issues of how to implement a citizen advocacy program were explained, including some cautions of things to avoid in implementation. Some discussion occurred of advanced issues around citizen advocacy.

Event 4
7 days live-in Event
HOW TO FUNCTION MORALLY, COHERENTLY, AND ADAPTIVELY AS A HUMAN SERVICE WORKER IN AN IMPERFECTIBLE WORLD OF INCOHERENT AND POORLY ADAPTIVE SERVICES

In order to survive as a human service worker with high moral ideals, with one's integrity intact, and hopefully also with some effectiveness within human services, one needs a special balance of world views, preparation and support. This workshop addressed part of this need.

The workshop explored some of the major values that underlie human services, and that must be addressed and in many cases challenged by a person who wants to become or remain a moral human service worker.

Participants were exposed to an array of strategies which are universal and therefore applicable to any planning project, service operation, voluntary involvement, advocacy relationship etc.

Event 5
1 day
THE HISTORY OF HUMAN SERVICES

This was a one-day pictorial presentation (with about 300 slides) on the history of human services that sketched the origins of many current service patterns and practices, and some universal lessons which can be learned from this history.

Event 6
1 day
THE IMPLOSION OF HOSPITAL MEDICINE DUE TO ITS HUMANLY UNMANAGEABLE COMPLEXITY

This presentation addressed the risks to the health and lives of hospital patients, especially those who are societally devalued, due to the complexity that characterises modern hospital medicine — a complexity that has grown beyond the human capacity to manage.

8.2 Appendix B: Timetable for Advocacy Workshop held in Perth, March 3 and 4, 1993

EDITH COWAN UNIVERSITY

Centre for the Development of Human Resources

in conjunction with:

MICHAEL KENDRICK

Director, Institute for Leadership and Community Development, Massachusetts, USA

Presents:

ADVOCACY WORKSHOP

Wednesday 3 March 1993

Session 1
What is advocacy?
This session will define advocacy, identify some of the essential elements of advocacy, and differentiate advocacy from other things which are often mistaken for it.

Session 2
What is the moral base for action?
This session will explore the notion of morality and propose a position in relation to the moral base for advocacy action.

Session 3
What is the position of advocacy in modern society?
This session will focus on where advocacy stands in relation to society, human services, the family and other social structures.

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Thursday 4 March 1993

Session 4
"Finesse"

This session will focus on the artful management of advocacy efforts.

"State of the Art"

This session will focus on contemporary issues specific to:

(a) citizen advocacy;
(b) parent advocacy;
(c) legal advocacy;
(d) self advocacy;
(e) systems advocacy.

Session 5
Priorities and leadership

This session will focus on the importance of developing priorities for advocacy efforts and the central role of leadership.

Session 6
Renewal, safeguards, moving forward

This session will focus on issues relating to the need for renewal and safeguarding of advocacy efforts to enable the establishment of quality and endurance.

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8.3 Appendix C: Contact Names for Australian and New Zealand Social Role Valorisation Training

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