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Aboriginal people with disability and their use of advocacy: A phenomenological approach

E. A. Leipoldt
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**Aboriginal People with Disability and their Use of
Advocacy: A Phenomenological Approach.**

E.A. Leipoldt

**A thesis submitted in partial fulfilment of the requirements for the Award of
Bachelor of Social Science (Human Services) Honours**

1998

Faculty of Community Services, Education and Social Sciences

USE OF THESIS

The Use of Thesis statement is not included in this version of the thesis.

Abstract

The reasons for an apparent low use of advocacy agencies in Perth by Aboriginal and Torres Strait Islander people who have a disability, in a context of high vulnerability, were investigated. A high incidence of disability exists amongst this group. No previous research in this area has been conducted. Nine Aboriginal people with disability were interviewed about their experiences with regard to their disabilities and any need for advocacy. This study used a qualitative, phenomenological approach as its conceptual framework, including also, a minor quantitative component. The quantitative component consisted of a brief survey of Perth-based disability advocacy agencies. It employed a semi-structured interview approach. This approach is a departure from the traditional, open-ended phenomenological method. Interviews were recorded on audio tape, transcribed and then analysed, using Colaizzi's phenomenological method. Aboriginal contact persons were used where possible to overcome cultural barriers and heighten the researcher's sensitivity to the vulnerabilities of the participants's double disadvantages of Aboriginality and disability. The researcher's own disability was considered an advantage in gaining the participants' acceptance. The findings of this study include a complete absence of awareness of advocacy or advocacy agencies among participants. As well Aboriginal 'shyness', poverty, effects of long-term discrimination, powerlessness, the wider Aboriginal background of abuse, not having Aboriginal workers in advocacy agencies and tensions between Aboriginal groups were identified as barriers to accessing advocacy. The use of 20 'wounds', obtained from Social Role Valorization theory, confirmed the validity of the findings. Citizen Advocacy was found to advocate for higher numbers of Aboriginal people

than other advocacy forms and this finding may lead to further research on suitable advocacy forms and adequate funding. Implications of this study, regarding funding of advocacy and development of suitable advocacy models in participation with Aboriginal people are highlighted. The study contributes to greater understanding of the reasons for low Aboriginal use of advocacy agencies.

DECLARATION

I certify that this thesis does not incorporate without acknowledgement any material previously submitted for a degree or diploma in any institution of higher education; and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made in the text; or contain any defamatory material.

Signature:



Erik Leipoldt

Date: 4th February 1999

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CHAPTER ONE INTRODUCTION

Advocacy is about addressing the issues of vulnerable people, yet Aboriginal people with disabilities seem to make low usage of it. This assertion was in part confirmed by an initial, short survey of Perth disability advocacy agencies. In this study some of the reasons for low usage of disability advocacy agencies in Perth by Aboriginal people who have a disability were examined.

Background

The Aboriginal population experiences particularly high rates of health-related disabilities compared to the general population (Bostock, 1991; Gething, 1995; O'Neill, 1993; Smeaton, 1996; Wolstenholme, 1996). One would ordinarily expect that the need for advocacy would be high in this group because disability increases vulnerability to abuse, neglect, discrimination and isolation (Cocks & Duffy, 1993; Cross & Zeni, 1993; Wolfensberger, 1992).

The impact of the disability on the person's life, the social circumstances including poverty, unemployment and lack of education, the impacts of the disability service support system plus societal attitudes to persons with disability, combine to produce a heightened vulnerability to harm and discrimination (Cocks & Duffy, 1993).

When people with a disability belong to any cultural minority group, it seems their disadvantage is multiplied. Studies of Canadian Aboriginal populations for instance confirm a similar picture to the position of the Australian Aboriginal population. The disability rate for the adult Canadian Aboriginal population (31.3%), for instance, is almost twice that of the total Canadian population (16.8%). For Aboriginal adults living on Indian reserves there, the disability rate is even higher at 33% (National Aboriginal Network on Disability, 1990).

Australian Aboriginal people have much higher than average rates of poverty, unemployment, and incarceration. In addition to these, lower life expectancy and lower access to education as well as issues of racial discrimination are part of contemporary Aboriginal life (Bostock, 1991; Gething, Poynter, Redmayne & Reynolds, 1994; Gething, 1995; O'Neill, 1993; Smeaton, 1996, 1998; Wolstenholme, 1995). These factors, combined with disability in particular, produce a highly vulnerable situation for individuals with disability who are of Aboriginal descent.

Background of the research

The researcher's personal background is considered relevant (Rew, Bechtel and Sapp, 1992). In his past employment as an advocacy agency co-ordinator in

Perth, and in his present role of convenor of a national disability advocacy network, as a recent evaluator of a major systemic advocacy group and regular presenter of advocacy theory, he has observed that it is not obvious that many Aboriginal people use the formal, government-funded disability advocacy agencies. The researcher has personal experience of significant disability over some 19 years. He is not Aboriginal.

It is essential in phenomenological research that the researcher puts aside, or at least makes explicit, their own assumptions and beliefs. The phenomenological techniques of “Epoche” and “bracketing” (Patton, 1990) were employed to overcome any tension between personal knowledge and experience and a level of objectivity.

Definitions

The terms ‘disability’, ‘Aboriginality’ and ‘advocacy’ are defined below.

Disability defined

For purposes of this study, which involves some advocacy agencies which receive joint Commonwealth/State funding, the Western Australian definition is adopted.

Disability, defined in the Disability Services Act (1993) is as follows.

“Disability” means a disability-

- (a) which is attributable to an intellectual, psychiatric, cognitive neurological, sensory, or physical impairment or a combination of those impairments;
- (b) which is permanent or likely to be permanent;
- (c) which may or may not be of a chronic or episodic nature; and
- (d) which results in -
 - (i) a substantially reduced capacity of the person for communication, social interaction, learning or mobility; and
 - (ii) a need for continuing support services (Disability Services Act, 1993).

Aboriginality defined

As a cultural group in Australia Aborigines are commonly referred to as Aborigines and Torres Strait Islanders.

Today there is official acceptance of Aboriginality when individuals identify themselves as part of the Aboriginal culture, are of Aboriginal descent and are accepted by the Aboriginal community as being part of it. This is how Aboriginality is defined for this study (Australian Bureau of Statistics, 1993).

Advocacy defined

The definition adopted for this study is the following:

“Advocacy is 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. Advocacy strives to be emphatic and vigorous and is actually, or is very likely to be, costly to the advocate” (Wolfensberger, 1992).

Types of advocacy defined

Citizen Advocacy

This form of advocacy facilitates advocacy-relationships between a person in need of advocacy (protégé) and an unpaid, voluntary advocate. (Forster, et al., 1997).

Individual Advocacy

This form of advocacy employs paid advocates to address the issues of individual people with disabilities. In addition, it may sometimes facilitate unpaid, informal advocacy.

(Forster, et al., 1997).

Systems Advocacy

This form of advocacy aims to achieve structural change of a wider nature within bureaucracies and the wider community as well as within disability service systems.

Like the other forms of advocacy, it is not based on complaints and is a different level safeguard to, for instance, the Disability Discrimination Act (Forster, et al., 1997).

Purpose and Significance of the study

The purpose of this study is to find the reasons for an apparent low use of advocacy agencies in Perth by Aboriginal and Torres Strait Islander people who have a disability, in a context of higher than average disability rates for this population.

Combined Commonwealth and State expenditure on advocacy in Australia stands at approximately \$14M (Office of Disability, 1997). Compared with Western Australian State expenditure on the entire disability support services system of \$247M, and Commonwealth expenditure in Western Australia of \$447M, including Disability Support Pensions (Rook, 1994), this is very little. There are no published accounts or other evidence of rigorous strategies being pursued by the funding bodies or any of the Western Australian advocacy agencies to ensure advocacy reaches the Aboriginal population.

In the absence of any specific advocacy, in Perth, aimed at the needs of Aboriginal people with a disability, it is likely that Aboriginal people with disabilities have less recourse than non-Aboriginal people with disabilities, to advocates who might right some wrongs or protect them from the effects of their heightened vulnerability.

At least one major report on advocacy in Australia has commented on a lack of advocacy for Aboriginal people with disabilities (Cross and Zeni, 1993) and that this should be investigated. Recommendations to the then Commonwealth Minister for Health, Housing and Community Services by the Disability Advisory Council of Australia (1993), based on this report, included that advocacy for Aboriginal people with disability be investigated because of its apparent non-existence. A more recent discussion paper, supporting a Commonwealth Review of the Advocacy Program (Office of Disability, 1997)

again specifically mentions this as a gap to be addressed. Yet, there is a scant body of knowledge which can inform the development of such advocacy. The only report in the area of advocacy and Aboriginal people specifically, was done by Smeaton (1996). He did not specifically address the reasons for and low usage of advocacy.

Most studies have investigated the rural and remote settings of Aboriginal communities, not the urban context, as in this study. The latter context is different, for instance because of its impact on Aboriginal culture and tradition, on perception of disability and because of a higher availability of services and advocacy.

It is important that the apparent low usage of advocacy, by Aboriginal people, is confirmed and that at least some reasons for low usage are known so that advocacy may be developed which does meet the specific needs of Aboriginal people. This needs to be known in order to understand and investigate what may work successfully.

Development of any new advocacy forms or adaptations, deemed able to improve Aboriginal use of advocacy, by existing advocacy agencies, without exploration of the issues which now stop Aboriginal people from using existing advocacy would possibly be harmful to Aboriginal people with a disability and could be financially costly.

Objectives of the Research

Objectives for the study are:

1. To identify influences and barriers to the use of disability advocacy agencies in Perth by Aboriginal people with disability and their families.
2. To establish an indication of use of disability advocacy agencies in Perth by Aboriginal people with disability and their families from these agencies.
3. To identify a common Aboriginal concept of 'need for advocacy'.
4. To identify the actions Aboriginal people with disabilities and their families take when in need of disability advocacy.

Research Questions

The research questions for this study are:

1. Which common influences or barriers to Aboriginal use of formal, funded disability advocacy agencies in Perth do Aboriginal people identify?
2. What is the level of use of advocacy agencies by Aboriginal people with disability and their families?

3. What are the experiences of Aboriginal people with a disability of the impacts of disability, particularly those which call for advocacy?
4. Do Aboriginal people with disability, and their families, recognise a need for advocacy?
5. What do Aboriginal people and/or their families do when they are in need of advocacy?

The findings of this research contribute to a better understanding of what appropriate forms of advocacy for Aboriginal people with disabilities, how advocacy may become more responsive and an understanding of how significant cultural differences in perspectives on disability and advocacy may be.

In summary, no existing body of knowledge on the reasons for this low usage appears to exist. Yet such knowledge is required to investigate appropriate ways of providing advocacy to this group. Currently, the Commonwealth funder of disability advocacy is expressing a wish to do something in this area. This research is especially significant as it is responding to an identified contemporary need at a time when there is a will, and possibly some resources, to do something about it.

Issues of the need for advocacy, heightened vulnerability, the cultural context and methodology are explored in the literature review.

CHAPTER TWO

LITERATURE REVIEW

The purpose for this literature review is: 1) to review research and other related literature on Aborigines, disability and the need for advocacy, 2) to review the literature on related research methodology, 3) to critically analyse the relevant literature.

This study is a descriptive, exploratory analysis in the context of a phenomenological framework.

To avoid a premature closure and narrowing to what may emerge in the field (Bryman, 1998; Denzin & Lincoln, 1994; Glaser, 1978; Patton, 1990) this literature review commenced tentatively at the research proposal stage in order to establish the need for this study. In phenomenology the literature review is usually completed after analysis of the data, as was the case in this study.

A literature search has not identified any studies on the reasons for low usage of disability advocacy by Australian Aboriginal people. Most of the information is available in forms, other than research articles. Therefore studies and other documents related to this research area, such as on the double disadvantage of Aboriginality and disability, and on need for advocacy, are used in this literature review.

The causes for the current state of health and disproportionately high disability rates of Aboriginal people cannot be understood in isolation. They are associated with their “loss of land, loss of culture, loss of identity, loss of children, loss of self-esteem and institutionalisation, discrimination, isolation, abuse, violence and murder” (Smallwood, White and Kotiw, 1997).

The Aboriginal Context

The effects of this history are still felt today (Crawford, 1989; Wilson, 1997). This painful social and political backdrop to Aboriginal experiences needs to be taken into account in research relating to Aboriginal people (Bostock, 1991a; O’Neill, 1993; Smallwood et al., 1997), as much as this needs to be done in researching disability issues generally (Ballard, 1993).

The seriousness of this broader context does mean that disability as an issue is not always seen as of great importance to Aboriginal people (Bostock, 1991; Gething, 1994; Gething, et al, 1994; Gething, 1995; O’Neill, 1993). Because of this it may be even more pertinent for Aboriginal people with disability to have access to appropriate and effective advocacy.

The contextual Aboriginal issues, other than distinctive disability issues, were interwoven into the lives of the participants in this study, and cannot be separated from the disability context.

Poverty, for instance, is expressed in homelessness and substandard accommodation for 30% of Aboriginal and Torres Strait Islander people in Australia. Their unemployment rate in 1996 stood at 38%, almost five times the national rate. They are far more likely to suffer from diabetes, tuberculosis, leprosy, respiratory and circulatory disorders. Infant mortality rates range between 3 to 4 times higher than for the whole of Australia and the life expectancy of Aborigines is some 17 years below the general Australian population (Brotherhood of St. Laurence, 1996).

In Western Australia the Kimberley Aboriginal Medical Services Council (1997) reports an Aboriginal infant mortality rate in Broome, a popular Western Australian holiday playground, of three times the whole of the state figure of 10 per 1000 live births, a mortality rate of Aboriginal children under five of 2.3 times the occurrence in the WA population, 3 times the risk for adults between 15 and 30 and 4 times in the 30 to 59 age group.

O'Neill (1993) reports an Aboriginal death rate from injury that is almost three times that for non-Aborigines. Alcohol abuse is responsible for a large proportion of these (Gray & Atkinson in O'Neill, 1993). Death rates due to injury are greatest between the ages of 40-65 in Aboriginal males. These are mostly due to road trauma, violence and suicide and result in impairments such as head injury, spinal cord injury and permanent injuries to limbs (O'Neill). Contributed to by the consequences of mental illness, Aboriginal men die at 10.3 times the rate of non-Aborigines (Gracey & Wyatt in O'Neill, 1993).

This picture is not projected to get any better. The Western Australian Department of Urban Planning and Development (1998) projects the population of seniors, for instance, in the WA Aboriginal population to decrease from 4.7% of the Aboriginal population in 1991 to 3.7% in 2006. This is in contrast to the general population trend where more older people are living longer. At the same time the entire WA Aboriginal population is expected to grow from 41779 to 61041 over the same period.

The Australian Bureau of Statistics' Ageing, Disability and Carers survey (1993) shows an increase in disability with increase in age for the general population. For the Aboriginal population however this is atypical as at higher ages there are proportionally less people alive and disability occurs at higher than general levels throughout younger age ranges.

Physical abuse of Aboriginal children who were removed from their families was found to be as high as 62.1%. In government institutions alone this was as high as 30.7% of submissions made to the National Inquiry into the Separation of Aboriginal and Torres Strait Islander Children from Their Families (Wilson, 1997).

Sexual exploitation and abuse were common stories given in evidence to the Inquiry. At least one in every six (17.5%) witnesses to the Inquiry reported such abuse. A similar proportion (13.3%) reported sexual abuse in Western

Australia (Wilson, 1997). The Report to the Inquiry mentioned that these children had no-one to turn to for protection or comfort and were rarely believed if they disclosed the abuse.

Cultural knowledge and indigenous identity was lost by many of these 'stolen children' and resulted in alienation. Separation from families and institutionalisation amounted to trauma for many (Wilson, 1997).

Grief and loss are constantly present in the lives of many Aboriginal people. Wolstenholme (1996) reports that the pain associated with separation of families is still very much felt. The frequent presence of death among the Aboriginal population, as reported above, has a high impact, starting in teenage years (Gray, et al in Wolstenholme, 1996).

High Aboriginal incarceration rates further contribute to loss of family members to the prison system and sometimes even to their deaths. During 1990-1994, Aboriginal deaths in custody was double that of Australia as a whole, that is 28% and 14% of all deaths in custody. One in four Aboriginal males aged 18 - 24 enter prison and Aboriginal people are three times more likely than non-Aboriginal people to receive a custodial penalty (Aboriginal Justice Council, 1995).

People with intellectual disability are over represented in the Western Australian prison system (Cockram, Jackson & Underwood, 1992). Aboriginal

people with intellectual disability could be considered at extremely high risk of incarceration, due to their double disadvantage.

Aboriginal children with disabilities do not normally enter school via early Intervention Services. Their disabilities are often detected by the teacher. Many parents are not aware of their child's disability and there are no trained professionals identifying people with disabilities in Aboriginal communities (Gething, 1994). Many of these children with disabilities do not go on to high school, they simply go on the pension. This is because many Aboriginal parents see education as pointless for their children with disabilities and don't know about any support services (Gething, 1994).

Oliver's (1996) social model of disability dismisses, what he calls, the "individual model of disability" (Oliver, 1996, p.32), which locates the problem of disability within the individual. He also dismisses the notion that disability problems arise from functional limitations or psychological losses. Oliver (1996) says that, instead, society disables people through their attitudes towards them. The literature only partially supports this position in the case of Aboriginal people with disabilities. It does where, for instance, society has excluded them from education and incarcerated them at disproportionately high levels. At the same time Aboriginal grief, violence and substance abuse are circumstances and conditions which may directly lead to impairments and, at least, functional disabilities, such as brain damage (O'Neill, 1993). For Aboriginal people, impairments and disability can arise directly from their

disadvantaged social situation as an oppressed cultural minority and their disability does not only appear to be caused by societal attitudes towards their impairments.

Quite amazingly, an Aboriginal culture and values structure remains. Their traditional values of conformity, tradition, security (Fogarty and White, 1994) interdependence, sharing and communality (Bourke & Bourke in Hartley, 1995, pp. 54-55) do provide a tension however, with a contemporary society which professes the value of these but largely acts on values of individualism, materialism and utilitarianism (Wolfensberger, 1992).

There is a clear need for this research. The issues that Aboriginal people with disabilities face are loaded heavily with the serious and multiple layers of abuse, discrimination, isolation and neglect that Aboriginal people as a whole are experiencing in Australia. While disability advocacy has a role to protect and advance the position of vulnerable people with a disability, it must be a concern to advocates, government funders, the Aboriginal and wider Australian community that advocacy does not play this role in the case of Aboriginal people with a disability.

Aborigines, Disability and the Need for Advocacy

Aboriginal people across Australia experience much higher than average socio-economic disadvantage and health related problems, which lead to disability (Bostock, 1991; Gething, 1994, 1995; Gething et al, 1994; Smeaton, 1996; Wolstenholme, 1996).

Bostock (1991 a) mentions common impairments among Aborigines which include impaired immune system, kidney disease, hearing impairment, multiple sclerosis and diabetes. In addition he lists alcoholism and drug addiction as common causes of impairment. O'Neill (1993) refers to much higher incidences for Aboriginal people, compared with the general population being found for chronic ear infection, blindness, acquired brain damage, diabetes, strokes and psychiatric illness.

Statistical information on disability rates of Aboriginal people is scarce (Gething, 1994; Gething, et al, 1994; O'Neill, 1993; Smeaton, 1998). The only available disability statistics are contained in the Survey of disability, ageing and carers, done by the Australian Bureau of Statistics (1993). It gives the disability rate of the total Australian population as 18%. Aboriginality was not identified in this survey. The Aboriginal rate is likely to be much higher (Gething,et al, 1994). An example of that is the Aboriginal disability rate in the Taree area where the level of reported disabilities among the Aboriginal

population was 2.5 times higher for males and 3.9 times higher for females than for the total Australian population. The levels of handicap were 1.7 times higher for males and 1.8 times higher for females, and for people with severe handicap was 2.4 times higher for males and 2.3 for females. While the prevalence of disability increased with age, as it does in the general population, the prevalence of Aboriginal people with a disability exceeded that of the general population in all age groups (Thompson & Snow, in Smeaton, 1998).

Data from the 1996 Census shows that Aboriginal and Torres Strait Islanders make up 1.38% of the total population for the Perth metropolitan area (Australian Bureau of Statistics, 1998). No disability statistics have been collected in any Australian Census, apart from the 1993 survey (Australian Bureau of Statistics, 1993).

Despite their significantly higher rates of disability, Aboriginal people tend not to access disability services (Gething, et al, 1994; Gething, 1995; O'Neill, 1993; Smeaton, 1996; Wolstenholme, 1996). Neither do Aboriginal people appear to be using Commonwealth-funded advocacy agencies (Cross & Zeni, 1993; Office of Disability, 1997), whereas one of the purposes of advocacy, as defined, would be to get them the services they need.

One might expect, that, since it is a role of advocacy agencies to address inadequacies in the service system for individuals and groups, that advocacy may be seen as different from services and consequently used to Aboriginal

people's advantage. Some reasons for non-access with regard to advocacy may be similar to the reasons for not accessing support services but this cannot be assumed, particularly not as the nature and purpose of advocacy, and generally, its image, differs from support services (Cocks & Duffy, 1993; Wolfensberger, 1977).

Whereas Smeaton (1996) has provided the only known study, thus far, on Aboriginal people and advocacy, and interviewed participants in both rural and urban communities, he did not ask them about the reasons why Aboriginal people were not using existing advocacy agencies. He focused on developing appropriate advocacy models for Aboriginal people with disability. His approach assumes that it may not be possible to use existing advocacy agencies. It also assumes that advocacy itself, a Western, Anglo-Saxon concept, is understood by, and appropriate to, meeting the needs of Aboriginal people, whereas this study leaves that open as a possibility that was examined. On the other hand, he did, like Gething (1995) in his related study, show sensitivity to the cross-cultural dimension by engaging an Aboriginal co-researcher and contact persons.

No research appears to have been carried out on reasons for low usage of advocacy agencies by Australian Aborigines with disabilities. There is however some related, though limited, material on the reasons why Aboriginal people do not access disability support services (Curry, 1992; Gething, 1994, 1995; Gething, et al, 1994; O'Neill, 1993; Smeaton, 1996; Wolstenholme, 1996). These

include distrust of government agencies and non-Aboriginal service providers, lack of acceptance of Aboriginal life and worth by service providers, Aboriginal workers not being available, service not going to the Aboriginal people in need, lack of Aboriginal liaison persons, different perceptions of disability, lack of knowledge about the service, unawareness of entitlements, Aboriginal shyness about working in mixed Aboriginal and wadjella (white) groups, lack of Aboriginal service providers, service provider assumptions that Aboriginal communities will look after their own discriminatory attitudes of service providers and Aboriginal people highly valuing their privacy (Gething, 1994; O'Neill, 1993; Smeaton, 1997).

Additionally, "Many Aboriginal people are not well informed about their rights, available services or about how to gain access to them" (Gething, 1994, p.42) and word of mouth is often the best way to disseminate information (Gething, 1994).

The literature shows some issues which lead Aboriginal people to under-use disability support services, as distinct from advocacy, including: Aboriginal people not being a homogeneous group - they are culturally diverse; disability being a different concept for Aboriginal people; continuing impact of past assimilation policy; mistrust of government programs; assumptions about Aboriginal people with disabilities and their families by service providers and professionals; culturally inappropriate procedures; bureaucracy; lack of planning for Aboriginal people with disability; reluctance to complain about

services (Smeaton, 1996) and shame associated with disability (Boslock, 1991; Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women's Council Disability Support Project, 1995).

Whereas much of current disability advocacy is based on rights ideology, O'Neill (1993) and Smallwood, White and Kotiw (1997) question the appropriateness of a human rights approach to Aboriginal issues and Bridgman (1992) has pointed to inadequacies in advocacy practice such as not being culture-specific, lack of independent funding, lack of training in advocacy, and lack of regular evaluation.

The situation of Aboriginal people with disability in Australia is one of serious disadvantage compared to the total population, submerged as it seems by the enormity of a range of other Aboriginal issues.

The purpose of this study is to provide some insight into the reasons for an Aboriginal low use of advocacy agencies. Further work may arise from the findings of this study, leading to the creation of advocacy models that are more appropriate to Aboriginal needs.

Methodology: Phenomenological Approaches to Research of Aboriginal People with Disability and their Use of Advocacy

A qualitative research approach was judged to be most suitable to the research objectives. Though a minor quantitative component is added in the form of a simple survey with six Perth advocacy agencies, the research objectives seek understanding, not a measurement, of why Aboriginal people with disabilities may not access advocacy. The study will present findings as experienced by the participants and very much treats the question as a moral enquiry (Sarantakos, 1993), befitting the advocacy context of social justice (Cocks & Duffy, 1993).

The nature of a phenomenological study is about accepting the experiences of the participants as valid in themselves. Because of the treatment of the subject as a moral inquiry (Sarantakos, 1993), which inevitably invokes personal feelings and beliefs of the researcher, "Epoche" and "bracketing" (Patton, 1990) will be used. These are phenomenological techniques of making any of the researcher's beliefs and assumptions explicit. Epoche is an ongoing process within the researcher where the aim is to maintain a fresh and open viewpoint without prejudging or ascribing meaning too soon. Personal assumptions and beliefs need to become explicit and set aside as much as possible until such time when all the data are in (Patton, 1990). Bracketing involves to:

Locate within the personal experience, or self-story, key phrases and statements that speak directly to the phenomenon in question.

Interpret the meaning of these phrases as an informed reader.

Obtain the subject's interpretation of these phrases if possible.

Inspect these meanings for what they reveal about the essential, recurring features of the phenomenon being studied.

Offer a tentative statement, or definition, of the phenomenon in terms of the essential recurring features identified in step 4.

(Denzin, in Patton, 1990, p. 408).

Aboriginal people prefer informal, oral means of research enquiries (Gething, 1995; National and Medical Research Council, 1991). This study employs qualitative research which uses words as data to describe human experience or behaviour (Bloland, 1992) and is best described through its characteristics including:

assuming that the social world is created as seen and experienced by individuals,

reality being captured in meaningful human interactions,

presenting information in words, not in numbers,

being wholistic,

aiming to understand, not measure,

seeing the researcher as part of the research (Patton, (1990),

the research is a moral enquiry (Sarantakos, 1993).

This research seeks the unique experiences of Aboriginal people. A phenomenological approach appears to be the most coherent among qualitative research methodologies where the essence of the participants' experiences of a certain phenomenon is sought (Colaizzi, 1978; Crotty, 1996; Field & Morse, 1990; Guba & Lincoln, 1985).

It has been indicated already that there is no literature, known to the researcher, on Aboriginal people with disability, and reasons why it appears that they tend to not use disability advocacy agencies. The closest related literature shows explicit examples of phenomenological or phenomenological case study approaches. Of the main, related, studies none sets out an explicit

methodological paradigm which may underpin their methods (Curry, 1992; Gething, 1995; Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women's Council Disability Support Project, 1995; O'Neill, 1993; Smeaton, 1996; Wolstenholme, 1996), while Bostock (1991) speaks from his own experience and insider knowledge. Interviews are used in all these studies, some semi-structured and in-depth (Wolstenholme, 1996), formal and structured (Curry, 1992), informal group interviews (Gething, 1995), group meeting (Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women's Council Disability Support Project, 1995), unstructured, individual and group interviews (Smeaton, 1996). Smeaton emphasises letting individuals tell their own story, in essence part of the phenomenological approach. Gething (1995) conducted a case study of a group and O'Neill (1993) included some individual case studies. All studies rely on information from some combination of individuals with disabilities, carers, families and service providers.

Studies in the non-Aboriginal disability advocacy area, such as Cocks & Duffy (1993) and Cross & Zeni (1993), all relied on semi-structured, informal group and individual interviews and did not state any methodological, paradigmatic underpinnings.

In summary, the literature in these related studies is silent on methodological paradigms but displays a uniform application of descriptive, informal, qualitative approaches.

Whereas not stated, it could be claimed that most studies, such as Gething (1995), the Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women's Council Disability Support Project (1995), O'Neill (1993), Smeaton (1996) and Wolstenholme (1996), did adopt a phenomenological approach to their studies by letting people tell their stories. None however used a phenomenological data analysis method.

Conceptual framework

This study's conceptual framework, shown in Figure 1., is based on the theory of phenomenology which is as much a world view as a research methodology (Field & Morse, 1990; McPhail, 1995; Patton, 1990). The phenomenological world view is essentially an existentialist one (Wyatt, 1997) which says that the individual defines their reality based on what that person knows through their experience (Patton, 1990). Therefore every individual's view of the world is held to be unique, as it is in this study.

The methodological approach is well suited to this study as it is about capturing the essences of participants' experiences in a naturalistic setting, allowing representation of the data in their own words. This is particularly appropriate in the Aboriginal cultural context (Gething, 1994) and in the context of disability as a highly personal and unique situation for each individual.

This paradigm was chosen as it appears that the situation of Aboriginal people is unique and the participants' stories are based on the essence of experience of Aboriginal individuals with disabilities and their associated world views.

A phenomenological approach accepts the individual's definition of reality without the researcher having preconceived notions, prejudices, expectations, theories about causes or processes (Field & Morse, 1990). Different theories, and their various respondents' interpretations, may, in qualitative research, be simultaneously valid (Mellon, 1990) however and further theory may develop from the findings of this study (Olson, 1997) through the researcher's and readers' insights.

The conceptual framework for this study, including its methodology is represented in Figure 1.

It is important that the conceptual framework remains flexible and is able to be changed as insights emerge (Marshall & Rossman, 1989; Miles & Huberman, 1984; Patton, 1990). Accordingly it was reviewed again, during and at the conclusion of data analysis. It remained completely relevant.

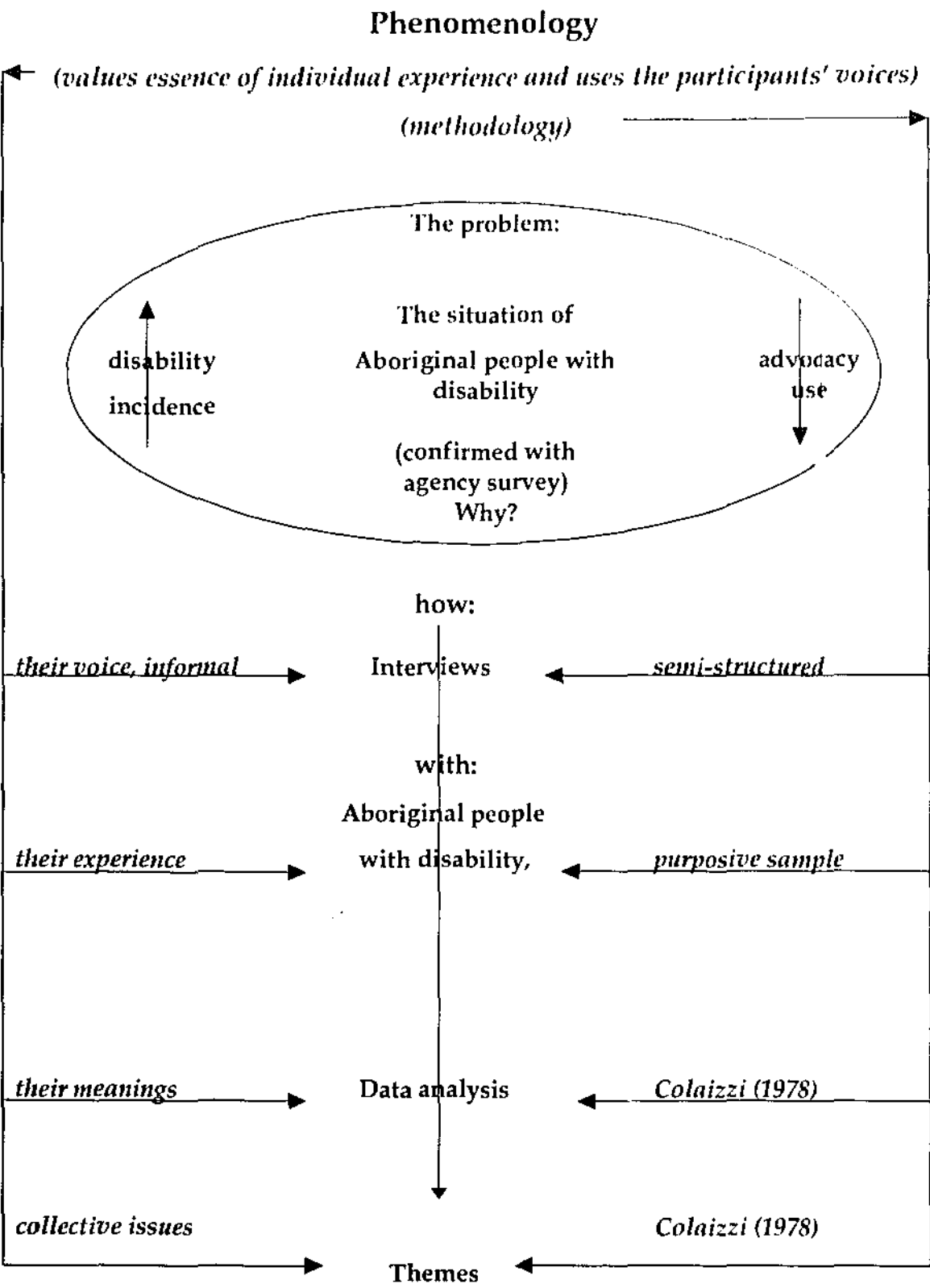


Figure 1. Conceptual framework of the study, showing the relationship of the methodological paradigm to the methods, in relation to the problem under investigation in this study.

CHAPTER THREE

BRIEF ADVOCACY AGENCY SURVEY

The purpose of this chapter is to establish an indication of use of disability advocacy agencies in Perth by Aboriginal people with disability and their families.

An important part of the rationale for this study was the researcher's assumption that Aboriginal people with disabilities under use disability advocacy in Perth. This was based on the researcher's experiences as a past co-ordinator of a disability advocacy agency and his knowledge of local advocacy practice as well as what the literature says about low use of disability services by Aboriginal people.

It was thought to be important to check that assumption by means of a simple, brief survey of Perth disability advocacy agencies, early in the research process. This was done.

Seven disability advocacy agencies were identified within the Perth metropolitan area. Two practised both individual and systemic advocacy, three Citizen Advocacy and two individual advocacy only. They were each sent a letter and brief survey, shown in Appendices B and D, and followed up by telephone where necessary.

Six agencies responded, with one stating they had not been operating long enough (since 1997) to fulfil the surveys requirements. Consequently this agency declined to respond.

One Citizen Advocacy Agency (Agency E), responded for the period from February, 1995, having been in operation for that time only. The agency had commenced with a certain number of proteges, having brought these matches with it when it developed as an independent agency from within another, existing, agency. Two of these were matches with an Aboriginal person. Consequently, some statistics for this agency show an unusual pattern. Another (Agency B) had only been in existence since March, 1995. Agency A indicated that data, referring to Aboriginal people may not have been kept for the entire five years.

The survey questions were framed differently for Citizen Advocacy agencies, than for other agencies, to accommodate their distinctive facilitative role. The nature of the questions was not altered in doing this. The survey questions are listed in Appendix B.

As this small supplementary study sets the scene for the rest of the study, the survey results and discussion are dealt with at this point.

Agency survey results.

The following tables explain findings made from a brief survey of advocacy agencies in Perth. All tables refer to a timeframe between 1st July, 1992 and 30th June, 1997, except for Agencies B and E.

Table 1

Number of Contacts Made for Advocacy by Aboriginal People, or Others, on their Behalf, Including the Number Identified in Need of Advocacy by Citizen Advocacy Agencies During 1992-1997.

	Number of contacts	Average per year
Agency A.	9	1.8
Agency B.	0	0
Agency C.	8	1.6
Agency D.	3	0.6
Agency E.	2	1.33

Nine Aboriginal people with disability, who were in potential need of advocacy, came to the notice of advocacy Agency A and 8 to Agency C. The other three Agencies had lower contact rates of 0, 2 and 3 contacts. Allowing for the different periods of operation of agencies B and E, yearly averages show Agency E. as having the highest number of contacts and Agency B with the lowest.

Table 2

Aboriginal Individuals Advocated for, Including Advocate/Protégé Matches

Made by Citizen Advocacy.

Advocacy undertaken		Average per year
Agency A.	4	0.8
Agency B.	0	0
Agency C.	5	1
Agency D.	3	0.6
Agency E.	3	0.6

Of those Aboriginal people who came to the agency’s notice, agency A advocated for 4 out of the 9 who made contact and agency C did for 5 out of 8. For the other agencies this was 0 out of 0, 3 out of 3 and 3 out of 2. This last figure is due to the history of establishment of Agency E, explained above. On average, Agency C had the highest rate of people advocated for, while Agency B had the lowest.

Table 3

Contact Made for Advocacy by Non-Aboriginal People with Disability or
Individuals Who Were Identified in Need of Advocacy by Citizen Advocacy
Agencies.

	Number of contacts	Average per year
Agency A.	2,965	593
Agency B.	207	138
Agency C.	57	11.4
Agency D.	56	11.4
Agency E.	16	10.7

Non-Aboriginal people came to the notice of advocacy agencies in much higher proportions. Agency A and B are responsible for strongly influencing the aggregate figures of non-Aboriginal contact with the agencies.

Table 4

Advocacy Engaged in on Behalf of Non-Aboriginal Individuals or

Advocate/Protégé Matches Made by Citizen Advocacy.

	Advocacy undertaken	Average per year
Agency A.	1,655	331
Agency B.	207	138
Agency C.	52	10.4
Agency D.	56	11.2
Agency E.	12	8

The advocacy engaged in on behalf of non-Aboriginal people is again at much higher levels than for Aboriginal people. Agency A and B, again, heavily influence the overall trend.

Table 5

How the Agencies Identified Aboriginality.

Agency A.	Identified by referral agency, mainly Aboriginal Medical Service.
Agency B.	Through information from 'consumer'.
Agency C.	Visual observation and talking to persons associated with the advocate.
Agency D.	Visual observation, person stating Aboriginality themselves, others disclosing Aboriginality.
Agency E.	Does not identify any advocate by Aboriginality but by need for advocacy.

It must be clarified that whereas some questions refer to an Aboriginal person referring themselves, the intention was to enquire about all self- and other referral of Aboriginal people with disability. It was obvious from the survey responses that the agencies had interpreted the latter. This was confirmed to be so through telephone enquiry.

Discussion

There is a discrepancy, in the Perth metropolitan region, between the proportion of Aboriginal and non-Aboriginal persons being referred for, or who actually received, advocacy (advocatees), in the selected advocacy agencies.

Over the five year time period, for all surveyed agencies, there were 3,301 non-Aboriginal persons who were referred, or referred themselves, to advocacy agencies against 22 Aboriginal people. There were 1982 non- Aboriginal persons who actually received advocacy compared with 15 Aboriginal persons.

In 1996 the Aboriginal population in the Perth metropolitan area was 1.38% of the total population, or 17,197 persons (Australian Bureau of Statistics, 1998) and the Survey on Disability Ageing And Carers (Australian Bureau of Statistics, 1993) gave an Australian disability rate of 18%.

Based on total population figures for the Perth metropolitan area, the surveyed advocacy agencies had referrals for 1.47% of the total, non-Aboriginal disability population and conducted advocacy for 0.88%. In comparison, 0.71% of the Aboriginal disability population was referred to advocacy and 0.48% received advocacy.

Applying the non-Aboriginal figures and the Australian disability rate of 18%, one would expect to see at least 45.5 Aboriginal persons being referred and 27 Aboriginal people receiving advocacy over the surveyed period. In reality, given a higher Aboriginal disability rate these figures would be expected to be higher. It can be concluded that at least 23.5 Aboriginal people were not referred to advocacy and 12 Aboriginal people did not receive advocacy over the period of the survey.

Additionally, it is known that advocacy for the non-Aboriginal population is reaching only a small proportion of people with disabilities who are in need of advocacy (Cocks & Duffy, 1993; Cross & Zeni, 1993). This seems confirmed by the finding of only 0.88% of this population receiving advocacy. It can be expected likewise therefore that an additional, unknown, number of Aboriginal people, in need of advocacy, did not receive it.

This study, while finding a low overall level of Aboriginal people accessing advocacy agencies, also found that this is not true for all advocacy types.

Table 6

Advocacy Referred to and Engaged in on Behalf of Aboriginal Individuals or Advocate/Protégé Matches by Advocacy Agencies.

	Aboriginal % referrals	% advocacy	% received advocacy
Agency A.	0.54	0.24	44.00
Agency B.	0.00	0.00	0.00
Agency C.	14.00	9.60	68.6
Agency D.	5.40	5.40	100
Agency E.	12.50	8.33	66.6

Note. For purpose of calculating this Table, a number of 2 advocacy matches were subtracted from Agency E's total figure for providing Aboriginal people with advocacy, as shown in Table 2.

Table 6. shows that Agency C, D, and E all have had contact with prospective Aboriginal advocates, and subsequently enabled advocacy on their behalf, at much higher levels than Agencies A and B. They did so at proportional rates that are higher than the Aboriginal/non-Aboriginal

population ratio for Perth, being higher than 1.38%, whereas Agencies A and B achieved rates below this level. On a yearly average agencies A, C, D and E were close in total numbers of Aboriginal people with disabilities being referred or receiving advocacy. In proportion to their non-Aboriginal workload, agencies C, D, and E did much better in advocacy for Aboriginal people in both categories, than Agency A.

The low access rate of Aboriginal people to advocacy agencies in Perth does not then seem a universal phenomenon. The three high-rating agencies are all Citizen Advocacy agencies. The other two engage in both systemic and individual advocacy.

The three Citizen Advocacy agencies also had much higher rates of Aboriginal people receiving advocacy, once people came to their notice, compared to the other two agencies.

Based on this small sample we can suggest that, in Perth at least, Citizen Advocacy agencies may be better placed to provide advocacy for Aboriginal people, compared to other forms of advocacy.

Agencies employed multiple means of identifying Aboriginality, ranging from visual identification to identification provided by self or other.

It is possible therefore that some Aboriginal people with disability were not known to the agencies. It is for instance not always possible to identify Aboriginal people by the way they look and individuals and others may be reluctant to disclose Aboriginality because of fear of discrimination and a sense of 'shame', or shyness (O'Neill, 1993).

This survey does have a number of limitations and must be treated with caution. It is based on a very small sample, not all agencies were operating over the surveyed period, possibly not all Aboriginal persons were thus recognised and one agency was unsure about the accuracy of their records on Aboriginality. It is however intended only to give a broad overall backdrop to the qualitative research. It validates the researcher's assumption that advocacy in Perth is generally under used by Aboriginal people. A most interesting aspect of these findings is that this phenomenon seems not applicable to a particular form of advocacy, that is Citizen Advocacy.

CHAPTER FOUR

METHOD OF INVESTIGATION

Seven disability advocacy agencies in Perth were identified from the researcher's personal knowledge and a check of a social services directory. A simple written survey amongst them established a level of their use by Aboriginal people. This survey is contained in Appendix B.

The main body of this study has followed a similar data collection methodology as most of the cited studies have, that is interviews with individuals.

Sample

Eleven Aboriginal people with disabilities were involved in semi-structured interviews for this study. Two were deemed unsuitable after the interview and were not used, leaving nine informants. The reasons for not including these two interviews were non-compliance with the definition of disability for one interviewee, and for the other non-identification with their Aboriginal heritage, preferring to see himself as non-Aboriginal. The geographical area covered was the Perth Metropolitan area. A sample of five to eight participants was expected to be sufficient for this study and indeed repetition of themes indicated an adequate saturation level for a study of this scope, with a sufficient level of rich data. Patton (1990) confirms that in qualitative research the sample

size is itself of less importance, in terms of validity, meaningfulness and insights gained, than the richness of information and analytical and observational capabilities of the researcher.

All participants met the selection criteria, which were set as having a level, and experience of, disability from which the researcher could reasonably assume that the individual vulnerability was such that advocacy was, or had been, needed in that person's life. Compatibility with the definition of disability was then assessed by the researcher.

Participants who met the criteria were expected to be especially information-rich.

Whereas an attempt was made to balance male and female proportions in the sample, this was unfortunately not possible, due to scarce availability of any informants of either gender and cancellation of interviews by two females.

Who the people in the sample were

Table 2. , shown in Appendix F, sets out the characteristics of the participants in detail.

Of those with spinal injury, one had paraplegia, two quadriplegia, of whom one had an amputated leg. The third was mobile with a walking frame and also had arthritis and diabetes. She relied on a walking frame for mobility. Two males had intellectual disability, one also having diabetes and the other vision impairment. Another male had a leg amputated, blindness and hearing impairment, all as a result of diabetes. He also had arthritis. One male had brain damage as a result of a car accident.

For two participants disabilities were acquired from birth, for two others at ages 7 and 19. Other individuals acquired their disabilities later in life.

Three participants lived by themselves and six with their children, wife, cousin or mother.

Two participants grew up in Perth, seven had moved to Perth from the country for reasons connected with their disabilities, that is availability of support services and hospital care. They came originally from Marble Bar, Kalgoorlie, Midland, Perth, Wubin and the WA South-West. Their tribal origins were Yamagee (1), Nyoongar (5), Wongi (2), Nyanga/Strelley (1).

During the period of this study, three participants were hospitalised since the first interview. One for treatment to abscesses on stumps of her limbs, one having his second leg amputated and one because of lung failure. The latter had to be on oxygen permanently after that episode.

Difficulties encountered in obtaining the sample

The sample is a purposeful one where, as explained, specific criteria for individual suitability as informants were formulated. These criteria and purpose of study were communicated verbally, and in writing, to all actual and potential contact persons. The role of a contact person was to lead the researcher to suitable interviewees and make initial contact with them. These contact persons were individual Aboriginal persons known to the researcher; workers in Aboriginal support services to people with disabilities, interviewees themselves, in an attempt at snowball sampling; and workers in a non-Aboriginal support service for people with disabilities.

It took a total of some five months to find and interview eleven informants, two of whom turned out to be unsuitable post-interview, following one participant not meeting the disability criteria and the other preferring to be known as non-Aboriginal, which, of course, did not meet the definition of Aboriginality. Three additional agreements for interviews failed to materialise. One of these prospective interviewees, who was visited at her home twice, was present the first time but declined to open the door and was not home when visited the second time. The other person received the researcher but the recording equipment unfortunately failed and no interview could be conducted on that occasion. The informant subsequently refused to meet with the researcher a second time. The third person declined to be interviewed upon

meeting him. Of course no pressure was brought to bear upon any persons expressing their unwillingness to participate. It did mean that on several occasions, where the researcher thought to have secured a source of rich information, this turned out to be not so and significant time was lost in this way and new efforts had to be made finding more informants.

Difficulties such as this, with individual informants, had been anticipated, because of the Aboriginal preference for informality (Gething, 1994), but the extent of time loss had not. What had not been fully anticipated was the difficulty in obtaining reliable contact persons.

All contact persons were expressing sympathy with the aims of this research and expressed that they could probably identify some potential interviewees. Many of these had to be contacted again numerous times to follow up on their assurances, often without results. Some potential interviewees were offered, only never to materialise. For instance, the researcher had been trying to make contact with one contact person in an Aboriginal support service who had initially 'promised' a number of informants. In pursuing other contacts he had obtained an appointment with a co-ordinator of another such service. When phoning on the morning of the appointment to confirm it, he was surprised to hear that that person had just resigned and he was now speaking with the person from the other service, who had, some months ago, 'promised' him some informants! He was then offered one informant if he would come in that morning and met with success.

On several occasions contact persons found informants who did not meet the disability criteria. The notion of a significant disability which had been experienced for some time did not always appear well understood. It appears that with some Aboriginal disability support workers the notion of disability included having diabetes, arthritis and other health-related diseases which, in some of the informants they proposed, had not yet manifested in any disability as defined in the definition adopted for this study, or had only been for a relatively short time. This should not be surprising as the causes for disability in the Aboriginal population are so often health related as well as being related to the effects of substance abuse and violence which arise from the disadvantaged position of the Aboriginal population in Australia (Bostock, 1991; Gething, 1994; Gething, 1995; O'Neill, 1993).

Interestingly, the notion of what constituted disability among the sample was clearly aligned with that which is accepted as the mainstream Australian idea of disability. This is explored further in the discussion of the findings.

The reasons given by the workers in Aboriginal support services included being very busy and staff changes. In terms of what is known about the overwhelming need in the lives of many Aboriginal persons the researcher accepts that providing informants for this study constituted a low priority for Aboriginal service workers. Disability often comes low on the list of issues that need to be addressed for Aboriginal people (Bostock, 1991a; Smeaton, 1998). In

addition, not many contact persons seemed to understand what advocacy was, thus perhaps not ascribing much importance to this study.

Aboriginal populations and workers in Aboriginal agencies could also be forgiven for thinking that this was yet another academic obtaining some qualifications out of reporting their lives and circumstances where Aboriginal lives have already been the subject of many a study, perhaps with little positive to show for it in their daily lives.

It is all the more reason why this researcher feels grateful and humbled by the willingness and graciousness of the informants in giving such a personal and in-depth insight into their lives and perceptions.

Likewise, the researcher is grateful and impressed by the contact persons' willingness and persistence in obtaining suitable informants.

Data Collection

Prior to collecting data from individuals, for the main part of the study, it was considered important to get an indication of present usage of advocacy agencies by Aboriginal persons. This was achieved by doing a simple written survey with the seven agencies identified by the researcher.

Data collection in a phenomenological methodology is about the uncovering of the essence of a phenomenon by gathering the individual stories about it, to interpret the stories and offering some implications for practice (Perl, 1996). This study, which adopts a phenomenological approach, does this. It is a relevant and appropriate methodology to collect data where it concerns individuals who have particularly suffered the effects of double disadvantage, such as this critical reference group appears to have, and where the findings do point to some implications for doing something about it via advocacy.

Because of the importance of cross-cultural considerations (Denzin & Lincoln, 1994) including norms, language and values (Patton, 1990), the researcher is not personally familiar with, he endeavoured to have an insider (Denzin & Lincoln), that is an Aboriginal contact person, present at interviews, wherever possible. He also used Aboriginal persons, where possible, to make contact with participants, take oral information, minimise written information, use flexible meeting times and tried to avoid jargon (National Health and Medical Research Council, 1991). It was not always possible to have an Aboriginal liaison, or contact person and, in the end, the net needed to be cast wider than just Aboriginal contacts. This issue has already been discussed under the heading "Difficulties encountered in obtaining the sample".

The interviews in a phenomenological study will usually be open-ended, with only one or two questions at its commencement (Patton, 1990). This practice was modified for this study where the sample included persons who have a limited capacity to communicate because of disability and because

specific areas under investigation, related to the research questions, needed to be probed for. Semi-structured, in-depth interviewing was therefore used. An interview guide approach was used and is attached, shown in Appendix A. It allowed for topics and issues to be determined beforehand but sequence and wording were determined during the interview (Patton, 1990). The researcher used some of his observations as data also.

The researcher therefore used a semi-structured approach with a number of themes about which answers were probed for during the interviews as necessary. A richness of individual detail was obtained which highlighted the themes.

Although the exact sequence of these questions or probes were decided during each interview, wherever possible Patton's (1990) approach was used, involving commencement with some general experience and behaviour questions, then about feelings, opinions and interpretations, followed by knowledge questions which require the established context with some relevant demographic questions last. It is interesting to note though that, on advice of an Aboriginal person giving feedback on the original, draft questions, the first question was to be: "where are you from?". This, for Aboriginal people, he explained, is not so much a demographic question as establishing with whom they belong, as it would often indicate the tribe, kinship relations and particular family, all of great importance to Aboriginal people. Thus, whereas to non-Aboriginal people it might seem a demographic question, which should be

asked last according to Patton, to Aboriginal people it is really a general experience question, fitting Patton's model in its very first stage, that of asking general experience questions.

The attached interview schedule and consent form were developed in consultation with an Aboriginal person who has some knowledge of advocacy, but is not a person with a disability.

Procedure

Participants were selected purposefully through making personal contacts with Aboriginal individuals and Aboriginal- as well as with non-Aboriginal disability service providers. The nature and purpose of the study, criteria for informants and process for seeking them, were explained to these contact persons. A brief written outline of these was made available to them.

They were then asked to contact potential informants, explaining the nature and purpose of the study, the background of the researcher, and ask for consent to be contacted by the researcher and pass their contact details and brief outline of their relevant background to the researcher. They were also asked to explain that a small sample only was needed and that the researcher would select the final informants and would let everyone who was not selected know as soon as possible. Upon the informants consent to participate, they were asked to

contact the researcher with names, some background detail and means to contact the informants. The researcher then contacted the participants.

Ideally, the researcher would have liked to use a snowball-sampling technique. This was attempted in some instances but because of the short time available and no new participants forthcoming in this way, the purposive approach was followed instead.

Participants were given some information on the study and its purpose for interviewing them, prior to the interview, so some prior thought could be given to relevant matters (Patton, 1990).

The interviews were interactions between researcher and participant (Sorrell & Redmond, 1995) where the participants were steered towards giving their perspectives on their experiences in their own words and the researcher engaged in active listening to understand and capture those meanings in the participant's own words. Narratives, story telling and anecdotes were encouraged in as rich a detail as possible (Patton, 1990).

Interviews took mostly around one to two hours each and were conducted in the participants' setting of choice, which in all cases was their place of residence.

All interviews were recorded and transcribed by a trusted person who undertook to maintain confidentiality. A summary of the interview was made available to the participants. Follow-up was then done via telephone interviews with each participant, apart from two, who could not be contacted again. One was too ill, the other did not respond to numerous phone calls and approaches through a contact person. Issues and questions that arose from the first interview were clarified with the participants and participants were encouraged to pursue unfolding themes from the previous interview. These were directly recorded in writing, including verbatim quotes where deemed particularly important.

Any pertinent topic areas not covered by participants towards the end of the interviews were probed for. Generally, the interview schedule ensured a comprehensive coverage.

Aboriginal contact persons were used as much as possible. Where not, persons who the potential participant knew well personally, that is support service workers, were engaged. Participants were encouraged to have family or a contact person present if they wished and six participants chose to do this. Two interviews were conducted in the open, in front of the participants' homes, the others inside their place of residence.

The researcher had become aware of Aboriginal 'shame', on reading (Gething, 1994; Gething, et al, 1994; O'Neill, 1993) and after talking with an

Aboriginal support worker prior to the commencement of the study, and from his own experiences with Aboriginal people in the Kimberley, with regard to their dwelling. Sitting outside was therefore explicitly offered to participants to overcome this.

A pilot interview was conducted, which became part of the data, to enhance the eventual approach and the researcher's interviewing technique. As a result of the pilot interview, subsequent interviews became a little more structured in ensuring the necessary issues relating to the research questions were covered but no change was made to the interview schedule.

Reliability and Validity

In general, the reliability of this research rests on the research design and the rigour with which the research was done, both of which were discussed in the previous section.

The validity rests on a suitable method of triangulation so potential for researcher bias can be minimised. To do this the researcher has used an alternative theoretical framework, that is the concept of 'wounding' (Wolfensberger, 1987) in Social Role Valorization (Wolfensberger, 1992), to re-analyse the data. In addition a colleague, well versed in phenomenological research, read and coded a transcript. This colleague substantially concurred

with the categories that had been identified by the researcher. Also, the themes were validated by checking back with the participants post interview.

Further triangulation occurred by comparing the data from the found essential experiences of the critical reference group with results of the survey of advocacy agencies and by verifying accuracy of collected data with participants.

Further, specific to this research, issues around cognitive impairment and Aboriginal cultural considerations relevant to communication between researcher and participants were considered prior to data collection.

Reliability, validity and intellectual disability

Three participants had a cognitive impairment, that is two had a developmental disability and one brain damage. The use of informants with such impairments can jeopardise validity and reliability because of doubts about the ability to respond to questions asked. Strategies to overcome such problems include using multiple approaches in inquiring about a topic and systematically checking for bias. Questions should be designed to maximise responsiveness, reliability and validity, and could be combined with non-verbal or behavioural observation techniques (Bruininks, et al, 1981).

Open-ended questions, of particular relevance to phenomenological research, in trying to obtain rich data, cannot be answered by many people with intellectual disability and are best asked as follow-up questions to more structured questions (Sigelman, et al, 1983).

While being aware of these issues the researcher found that the three participants in this study were able to understand and respond to the questions asked. This may partly have been aided by the research's departure from open-ended questions to semi-structured ones, for reasons already explained. The data provided by respondents with intellectual disability and brain damage matched data obtained by other respondents in terms of general content. It was concluded that the reliability and validity of this study was not undermined by the approach used with these respondents.

Reliability, validity and Aboriginality

Modes of interpersonal communication for any cultural group will be based on their cultural upbringing and belonging. Harris (1984) mentions long periods of silence; being softly spoken; talking being used more as a 'cement' in social relationships than the tool for transfer of information; shyness in talking with wadjellahs, or white people; and avoidance of eye contact as issues in Aboriginal communication. In addition different use of grammar, answering any leading questions according to the direction that is suggested and

prevalence of hearing impairment all affect communication between white and Aboriginal persons ("Directions to jury", 1998).

The researcher kept such issues in mind during interviews and further guarded against loss of reliability and validity due to cultural factors by submitting draft interview questions to an Aboriginal person in his acquaintance who gave feedback which resulted in some amendment of possible questions.

Data Analysis

The method, based on Colaizzi (1978), with some modification from open-ended to semi-structured questioning, involved interviewing the selected participants and the following steps were used:

Review of the literature on relevant research in the areas of Aboriginal culture, disability and advocacy.

Doing in-depth (semi-structured in this study) interviews, collecting participants' descriptions of their experiences as Aboriginal people with disability and their use of advocacy.

Keeping field notes of the researcher's experiences, insights and decisions.

Listening to the tape recordings and reading transcripts of recorded interviews several times to absorb them. Recording of researcher's reflections.

Significant statements and terms were then identified and categorised.

They were clustered into themes. With these the researcher referred back to the transcripts to verify them.

Results from the data analysis were used to write exhaustive descriptions of the experiences of Aboriginal people with disability.

Returning to participants to verify the descriptions of their essential experiences. This was done as much to clarify the identified themes as the descriptions of their experiences.

Further material was then added to the literature review.

Discussion of the findings and results in the light of the conceptual framework and literature.

Further analysis was then done using Wolfensberger's 'wounding' (1987) concept in Social Role Valorization (Wolfensberger, 1992).

Ethical Considerations

Participation was by informed consent only and participants were informed that they could withdraw at any time. In the case of persons with diminished capacity to make decisions in this respect, the researcher was willing to respect the wishes of such participants and liaise with the family, primary carer or guardian to confirm consent was given. It was the researcher's view that the participants with intellectual disability in this study were sufficiently responsive, able to understand the reason for this study and its confidentiality safeguards. Consequently, this was not necessary in this study, nor would it have been desirable with at least two of the participants with intellectual disability, given their significant conflict with their immediate families, as well as problems of geographical distance with one. Consideration was given to people with intellectual disability in terms of particular ways of asking questions and obtaining their answers (Sigelman, et al, 1983).

The security of tape recordings and transcripts was assured through their locked storage with sole access by the researcher.

A number was assigned to each participant to ensure their anonymity and confidentiality of information provided.

Data are reported as group data and no identifying data was used.

Upon completion of this research all tapes were destroyed immediately. All transcripts of these recordings are held in safe storage for five years and will then be destroyed.

The researcher undertook to not do anything, or publish any material, which may be harmful to the participants during any stage in this study, or after.

Five participants were presented with a summary of the completed interview transcript in a comprehensible format. By their agreement, two did not receive a copy because confidentiality might possibly have been compromised. Because of the explicit nature of issues such as sexual abuse raised therein, two participants' limited eyesight and the lack of ability to assure safe storage by these participants, they were only read a final copy over the phone. Two participants could not be contacted again, due to their illness and inability to re-establish contact.

Limitations

It has been argued that to fulfil both roles of researcher and advocate, as this researcher does, is problematic as researchers need to remain dispassionate while advocates need passion (Gelles, 1994). Avis (1994) on the other hand, calls this a false dichotomy and calls for greater complexity in the consideration of this issue. This researcher recognises a tension between the two roles, but believes that in this research his background in advocacy is a benefit, allowing greater in-depth consideration of issues. It may be arguable also whether the assumption that researchers need to be dispassionate is correct. Certainly, in this study, long-term passion regarding human injustice has played a major part in sustaining this researcher in conducting this work.

Any limitations were anticipated to most likely be pre-existing advocacy constructions in the mind of the researcher, possibly occluding any Aboriginal expressions of advocacy raised in interviews. However, perhaps in part due to urbanisation and an apparently high level of contact with white persons and their culture plus an identified loss of Aboriginal culture, no particular, Aboriginal ideas of advocacy emerged. The main alternative to 'formal western advocacy' raised was advocacy by family members and service workers, which could be considered a common advocacy approach with the wider non-Aboriginal culture.

As is also explored under 'Researcher and informant relationship', the researcher was able to link two participants to an advocacy agency. The researcher considers that, as a moral inquiry, doing so could not, indeed should not, be avoided for sake of, for instance, a rigid approach to 'objectivity'.

Involving service providers in finding participants may be considered somewhat problematic given that advocacy often stands in contradiction to support services, thus creating a conflict of interest situation. One way to deal with this was for the researcher to make this situation explicit. In practice, where this was thought to be a potential issue, service officers and workers, where they were contact persons, were asked to leave the interviewer and participant by themselves after introduction, and after consent for this to happen was given by the participant.

Further, it was possible, because of the participants' heightened vulnerability, that the validity of this research would be adversely affected by the respondents' perceived power and cultural imbalances, and therefore may not be entirely truthful (Demi & Warren, 1995). This was, at least in part, overcome by the use of Aboriginal contact persons wherever possible (Barn, 1994; Curry, 1992; Gething, 1995; Smeaton, 1996; Wolstenholme, 1996), the non-threatening nature of questions and the identification of participants with the disability of the researcher, who had quadriplegia and used a wheelchair. Again, further discussed under 'Researcher and informant relationship', the

commonality of disability between researcher and informants is likely to have enhanced acceptance and openness of communication.

The researcher was prepared to use group interviews if access to individuals proved too difficult, showing design flexibility. It came close to being necessary, but in the end did not need to be resorted to as enough individual participants were found.

The research process

This section reflects, more than any other perhaps, the interrelationship between researcher and participants. It is important to be aware of its potential influence on the results, as is discussed under "limitations".

Reflections on the research process.

This study did not merely set out to explore the experiences of Aboriginal people with disability and explore their meaning, as a purely phenomenological enquiry would do (Patton, 1990). It also employed the use of specific research questions in focussing on the specific purpose of this study, being the quest for reasons why Aboriginal people with a disability appeared to not use advocacy agencies in Perth to any great degree. A semi-structured interview structure was therefore used.

This has led to an increased richness of data with specific relevance to this enquiry as participants, during the interview, were brought back to the specific areas under investigation. At the same time the phenomenological approach ensured a first-hand look into the personal experiences of the informants, relevant to the questions. These experiences then provided important insights into the interactions between Aboriginality, disability and advocacy.

Researcher and participant relationship.

In this study, being an 'insider' was considered to be an advantage.

The researcher and informants had disability in common. It is relevant to state here that the researcher had a long-term, visible disability, being quadriplegia and involving the use of a wheelchair. It is commonly recognised as a 'severe' disability and the researcher shared certain experiences with informants, including relatively frequent hospitalisation; institutionalisation (though briefly); certain family dynamics and disruption; being the subject of an ongoing range of support services; some illnesses associated with long-term disability and being exposed to the medical model approach to patients and service users. The quadriplegia was probably most relevant where the three informants with quadriplegia were involved, having something so specific in

common, but it is felt, it also provided an important point of recognition and acceptance with the other informants.

This commonality has likely contributed to greater openness and acceptance of the researcher by informants although, in some ways, it is possible that this has contributed to some other influences in the participants' responses.

This might have included, in the case of informants with quadriplegia, keeping some matters private. It is a fact that within Perth, many people with spinal injury know each other, or at least are aware of others, and there is a likelihood that at some time they will meet in hospital. The researcher, was aware of this issue during interviewing. The great level of openness about very personal experiences, feelings and thoughts by most participants, including those with spinal injury, suggests it did not play a great role.

It could have been a relief to some that they were not talking to a 'professional' where they are asked to explain their circumstances to someone who might not understand their situation. It might have counted for something that the researcher explained his personal interest in, in advancing advocacy for vulnerable people with a disability as a dominant rationale for this study, besides obtaining a degree.

No researcher is ever totally objective and so will always influence the behaviour of the participant (Minichiello, et al., 1990; Van Manen, 1990), including that of non-human, or even inert subjects (Capra, 1983). It is a matter of being cognisant of this and to note any influences.

As a result of the interviews two participants were introduced by the researcher to a Citizen Advocacy agency who obtained advocates for them, another example of researcher/informant interaction. The researcher considered that as this research is also a moral inquiry he would play the additional role of introducing participants who could clearly benefit from advocacy, to a competent agency. This was done after interviews were conducted and approved by the participants and so this intervention was unlikely to affect the data anyway. One of these people (not used in the study, being ineligible on Aboriginal criteria) obtained a much needed electric wheelchair through a Citizen Advocate, plus ongoing assistance. Another was matched with a Citizen Advocate and received help in obtaining the best possible supported accommodation option for him.

In keeping with the findings of this study, these instances vividly illustrated the power of advocacy that seeks out people in need, rather than expect them to contact the agency, as well as the finding that Aboriginal people in this study considered it of more importance to receive competent advocacy than attaching overriding importance to by whom, that is an Aboriginal person, it is to be delivered.

Reporting abuse

Three times participants reported experience of sexual abuse. One only alluded to it and refused to talk about it. Two others were frank in what had happened to them. One had the perpetrator dealt with in court. In the case of the other man, who related sexual abuse by a service worker when a child, and another attempt from a worker at a different disability service at different times, he stated that he had met the first abuser in more recent times. He also stated that he thought the man had abused many Aboriginal children and thought he had now passed away. He later contradicted this by raising the possibility that he might still be alive and still be abusing children:

I even came across the fellow last year or the year before and asked him why he did do it, because I could never understand. But of course he'd forgotten about all that sort of thing and I suppose he did it with many other Aboriginal children, boys and girls. I think he's passed away now. If he's still living he'd still be mucking around with children I guess. He used to work for a place called.....which is pulled down now.

The researcher now faced deciding whether to take any action based on this information, in order to stop further possible abuse of others.

All participants signed a consent form that included a clause, alluding to the researcher's obligation to report criminal matters if the participant raised them. Off the record the researcher probed the participant who then said he

was sure the perpetrator had died. When offered to see if the researcher could find an advocacy agency for him he refused. Based on that information and after discussing it with the supervisors, it was decided that no further action should be taken by the researcher.

CHAPTER 5

RESULTS.

In this chapter the research results are presented. The findings, which were derived from the interviews and small agency survey, are discussed with reference to the literature and conceptual framework in Chapter six. A level of triangulation with Wolfensberger's (1987) wounding theory is provided separately in Chapter six also.

Findings and results from interviews

This section reports on what the data show and what meanings arise from these.

A considerable amount of rich data was obtained through interviewing the nine participants. This was examined for clusters of meaning and themes from which categories emerged (Colaizzi, 1978).

Four categories emerged from the material and were analysed. Under the various category headings a number of themes are discussed. Quotes from the interview transcripts are used to support findings and results.

Categories of themes

The four categories that were identified from the themes were:

Category 1: The wider Aboriginal context of disadvantage.

Sub categories:

Poverty

Unemployment

Education

Accommodation

Powerlessness and acceptance of circumstances

Imprisonment

Discrimination and abuse

Category 2: Loss of culture, family and relationships.

Sub categories:

Loss of family and relationships

Death

Loss of culture

Spirituality

Category 3: Disability and its impact.

Sub categories:

Concept of disability

Impacts of disability

Institutionalisation

Category 4: Knowledge and awareness of advocacy and barriers to it.

Sub categories.

Advocacy concept

Family feuds

Tribal and racial differences

Shame and shyness

Category 1: The wider Aboriginal context of disadvantage

In this category the participants' experiences and perceptions of the Aboriginal context are reported, in particular those experiences relating to the double disadvantage Aboriginality and disability has meant in their lives.

Poverty

All informants were dependent on a Disability Support Pension and some found it hard to manage with this.

I needed help with some bills.

I'm thinking about transport, I'm thinking about money, I'm thinking about my budget. If I'm going to live in the middle of nowhere I've got to remember that I've got to pay money to go to the shops and pay for a taxi all the way back home, pay for a taxi to go all the way to Shenton Park and back and that's not cheap even though I get 75% off. People say it's only \$10.00 or \$11.00 and I say maybe only \$10.00 or \$11.00 to you. I cannot work, so what am I going to use as support?

One participant related how she could not afford to buy a small garden shed to keep her equipment and other materials. Another spoke about the difficulty of saving up \$300.00 to go and see his relatives in the North-West.

The subject of poverty did not come up directly in many interviews. The researcher did not rely on verbal stories alone to try and understand the position of the participants. Observation also informed the research.

Two out of the participants had their own car.

Two had telephones which could only receive incoming calls because the telephone company had discontinued the outgoing connection pending outstanding phone bills to be paid. While in hospital, one participant could not afford to pay for his telephone, by his bed, to be connected, a matter of \$5.00 to \$10.00 per week.

Where the researcher entered participants' homes, there often was evidence of few and well-used belongings.

Unemployment

No participant was currently employed. Two attended TAFE. One had just published a book on his life and was in the process of writing another. Two said they could not work because of the disability. One was in her 60's and a householder. Two said they were "too lazy", making it seem as if they did not care.

I had work experience in year 9, went to kindy as a teacher, learning that, then the library, then Telecom. That was good . I liked that one.

They could not keep her there:

No, I don't know why, but it was really good. I tried to get back into it but....

When asked whether she wanted to work now she responded indirectly:

oh no, not really, no, I am too lazy now.

One participant who had had sheltered workshop experience expressed at a first interview that he was waiting for “his social worker” to list him with a competitive employment agency to find work. Some months later, on second contact, he was still waiting but had now just had an interview to take up sheltered employment again, incidentally at the same agency where he experienced sexual abuse as a child.

I’m hoping and I’m waiting so I can contact the two employment agencies who spoke to me last year about maybe working in Coles, stacking things up. I find that sounds like a fantastic idea.

Among the participants he was the only one looking for work.

Past history of employment included one week as a kitchen hand, sheep shearing and administration officer for only three participants. The others had never been employed. One other participant had sheltered workshop experience.

Education

Two participants currently attended TAFE, both in mainstream classes. One had paraplegia and one had an intellectual disability. A man with intellectual disability who attended a TAFE class said:

...sometimes I have problems in school with the teachers. She jumps at me and I cannot concentrate with her shouting at me all the time. Mainly it is in the college that I am having difficulties because I'm having nightmares or something like that.

The other man said that he had done some creative writing classes at TAFE “much later in life” after attending high school for some time.

One participant only, had completed Tertiary Entrance Examination.

A man with paraplegia who lived in the country before his accident, who had attended school till year 7, re-discovered, as a side benefit, some of his Aboriginal roots when attending TAFE.

I am more included in the Aboriginal culture now. I used to mix with both white people and Aboriginal people. Since I've been going to TAFE I've learnt a bit from other Aboriginal people and mix more with them now. Until I went to TAFE I did not realise how much hurt there was among Aboriginal people in Perth.

Most participants did not attain a high level of formal education.

Accommodation

Several participants expressed they had had trouble with the state public housing body in Western Australia.

Troubles ranged from complaints about having family stay over to not getting the right accessible features installed.

The first house they put me in was like no access at all. I couldn't get into the bathroom so that meant no weekend leave. There was no room for a hoist. It was that small and cramped, it was ridiculous.

On several occasions participants told of having been allocated inappropriate housing by the public housing authority, before more accessible accommodation was provided, in two cases purpose-built.

I was in Balga because like I said, I had both my legs off and I had a house in the Balga area and I couldn't reach the cupboards and that's when lady from the women's refuge thought of the idea of me having my own house because all the cupboards are now right at my reach. I had to be in the wheelchair and I couldn't go to the toilet because the thing was that small trying to get through, and the showers were all small too. I ended up getting somebody to come out and talk about getting a new house for me.

Having family come to stay for a while was a problem for two men, as the public housing provider frowns on this.

...I made a bad name for myself in this house. In a couple of days I had a bad name. Sometimes people would sleep in here, they'd just find a bedroom...It's up to me but it's up to Y (the public housing body). That's the reason Y don't want me to let them sleep here, but I have to drive them home otherwise. A people are coming around and coming to check on this house and find someone sleeping here and you have to ring the police to get them out...

Public housing was obtained by third parties for a few participants, including a social worker, an Aboriginal health service and a worker in a Women's Refuge. One man described a Mental Hospital getting him public housing accommodation.

I was in X (mental hospital) for a while and when they sent me out Y (public housing authority) got it for me. I was in X for two days and they ended up getting this house for me. X helped me. It was quite good. I can live in peace for a while.

One participant, now living in an Aboriginal hostel, said he wanted to obtain public housing, to live in by himself, even though he thought it might be lonely. He relies on a social worker to make this happen, and trusting this process declined an offer by the researcher to be put in touch with an advocacy agency that might help. So far, he has been waiting seven years and is yet to be offered public accommodation. One of the reasons for wanting to live by himself may have been his previous experience of having been taken advantage of by his family.

I even had lots of arguments with my older brother. Within the laws of Y (public housing authority) house, if you share a house..., well for instance my brother wanted to charge me \$100,00 or \$300,00 or something for the rent and I wasn't living with him, I was living with my grandmother".

Powerlessness and acceptance of circumstances

Most participants had not initiated many actions themselves to improve things in their lives, some had.

Some learned that if they complained no action would be taken anyway, and this might have worsened their situation. One recounted how, on reporting sexual abuse as a nine year old no action whatsoever was taken and the abuse continued.

I told the manager but he didn't do much of anything.

And when the same person was sexually harassed again later in adult life by a support worker, all that happened was that he was offered a change of worker. The offence was not pursued by those who employed him.

...there was a fellow they sent from some company who was supposed to act as a brother to me, take me out ten-pin bowling or whatever on weekends and he took me to the pub and it was enjoyable and of course he keeps touching me on the backside all the time.... I reported it to the social worker and I was offered another buddy.

Others learned to accept their situation as unalterable.

No complaints. No use asking for any more I suppose, take what you get and be happy with it.

Beggars cannot be choosers.

This same attitude was reflected by a mother of two sons with brain damage.

Whatever happened, happened, you're lucky to be alive, that's the main thing I suppose.

A participant with brain damage was also philosophical about his lot.

I suppose it was meant to be. I just wish I was a normal person sometimes but no one is perfect eh?

About using doctors, acknowledging that advocacy and help was sometimes needed to get something done, one man said:

If you approach them yourself, you've got no hope of getting anything.

On the other hand, a woman with arms and legs amputated did not feel there was anything much that should be changed in her life. She described how the white family she was being raised in was good but didn't let her do enough for herself, so she "ran" away to a women's refuge and learnt to cook and wash herself.

I don't find anything really hard, I do things myself. I had to do it myself when I left Z (her home town).

Again though, this woman did not initiate a move to accessible public housing accommodation when she needed it but this was facilitated by a Women's Refuge worker.

Imprisonment

Three informants had been imprisoned. All were male and had an intellectual disability. Two talked about having been imprisoned in a matter-of-fact way and could not identify areas of discrimination or abuse while imprisoned, apart from finding it "hard". One mentioned being protected by his nephew who was incarcerated at the same time. A third was frightened by prisoners fighting among themselves and a prison officer, who saw him as not coping, organised a social worker to visit him.

Participants were, understandably, not very forthcoming on reasons for their imprisonment. It included disorderly or offensive behaviour.

I've been in the lock-up for girls and for fighting.

Another man with brain damage had been imprisoned in Fremantle Prison, long since closed, where he said he found it hard but was able to look after himself.

I had a fight with a murderer. He reckoned he'd try and pull it over me, so I said I'm not frightened of you and I hit him and at that time my knee twisted and I grabbed hard on my leg. I had long hair and he grabbed me by the hair pulling me. ...I got to my feet and he came back with a belt and swung the buckle at me. I grabbed it and pulled it off him...after that he never give me any trouble. I sort of straightened him out, one way or another.

Discrimination and abuse

Participants offered some specific examples of incidences of discrimination and abuse.

A man with visual impairment related an instance of abuse by the public while being bemused by the possible cause for it.

...it was late, the trains were finished and I decided to walk all the way back to B..... I sort of got a bit tired along the way, almost sleepy walking and somebody drove past me and threw an egg at me. I didn't know what it was, so I happened to go to a petrol station and I asked a policeman who was there. I didn't know he was a policeman. He was in uniform and I couldn't see what was thrown on my face until I asked him and he told me it was an egg. I couldn't understand why the person did that, maybe because I had this particular watch that used to make a rooster noise all the time?

A young woman, with children, identified as the only area of discrimination, the bad treatment she got from taxi drivers.

I have had a lot of trouble with taxi drivers, if they see I'm Aboriginal they'll take off. They won't pick me up even when I am standing there with my arms showing them that I am (sic) disability you know, they just drive past. That's sad when they do that. It could be a cold night and my kids and me could be standing outside school waiting for a cab you know.

Sexual abuse occurred to a man with intellectual disability as a child, by a service worker, from within the service system that was meant to be helping him.

I find it hard to forget things, but of course, I've got things that will help me to forget. Things like abuse and sexual abuse... That was when I lived at the... school a long time ago. When you are a child, especially if you're an Aboriginal child, if you come to the city and you meet a fellow you would think would look after you pretty well and take care of you, and then they just use you for only one thing. Especially if you never knew about sex.

Another man with intellectual disability told of sexual abuse by his uncle. By contrast, a service worker had helped him, successfully, to take the issue to court.

Several participants explained that discrimination could also be experienced as coming from other Aboriginal people, particularly where an individual might have a mixed Aboriginal/white heritage, as one participant explains.

I do get treated wrong way and I get used by white- and full blooded and three-quarter and even half. They treat me like I was different. Family, they don't have much to do with me. When I'm home they treat me like a child and I feel so out of place, like I'm not a part of it. When I come back to Perth, well then some of them treat me like I was an Aboriginal. When I'm home some of them treat me like I am a white person.

Particular family names were associated with a “bad name” and two participants said they wanted to change their names so they would no longer be associated with their particular Aboriginal family. This wish was expressed in relation to their image with the public housing authority and was also connected with inter-family fights.

A female participant answered in the affirmative when asked whether discrimination because of Aboriginality was worse than discrimination because of disability. One man put the discrimination and abuse in the context of the overall situation Aboriginal people experience in Australia by saying;

We are visual aliens in our own country.

Category 2: Loss of culture, family and relationships

In this second category participants refer to their losses of relationships, family and culture and their feelings about these.

Loss of family and relationships.

In asking about family contact six participants did not have any or little family contact. Four of those spoke of that loss by stating they did not contact any more. As one individual said:

“No, I just like to be on my own sort of thing you know.

Some lost contact with family because they could no longer, because of the disability, travel around to visit family members as one man with quadriplegia described.

I was a tear-away when I was a young bloke like we all were I suppose. I suppose because of my Aboriginal- you know, the wandering, you cannot do that any more so you loose contact with your inner family, you’ve still got your brothers and sister, your mother and father. Because I am an Aboriginal and come from an extended family every now and then we used to take off to see aunty such and such or uncle so and so, and we might camp there for the night but you cannot do that in a wheelchair.

At the same time, this man also expressed a wish to keep distance from his family. He said that he couldn’t afford having his family to come and visit him.

I had to separate myself from my Aboriginal culture, I cannot keep open house for them if I want to survive and stay healthy. It means I never see my brother any more and that is painful.

A participant who as a child spent much time in Princess Margaret Hospital explained that being away from her home area so frequently meant she lost contact with family members. Another confirms that this is no isolated occurrence for adults either.

I've seen my people come and go from hospital because they don't look after themselves. The government does have an added responsibility for Aboriginal people because they're taking them out of a culture and putting them into a different place, then they're sending them back to their culture...

The loss of family and loss of relationships are of course, often, closely related matters. There was little opportunity and time for maintenance or development of relationships with family for those who were often hospitalised, away from their family. This was particularly impactful for children, such as was true for three of the participants.

I never lived with my family, like I said I was brought up with white people. And so they just come and see me on the weekends, you can't go through weekdays because of the schooling and that. They used to just come weekends and take me out. Everyone knew me but I didn't know them, know what I mean?

One sister I haven't met yet but the rest of the brothers I have. I think my sister might be around here somewhere but I haven't met her yet.

One of these participants has regained a small measure of contact with her family. Another felt completely alienated:

I feel like a lost soul. I may be on Earth for a very long time. I feel almost like an angel, you know, who will report to heaven. It is not easy being a human.

Death

The ultimate loss of family could be said to be when death occurs. Death was an inherent part of Aboriginal experience for a number of participants. Indeed, during the course of this study one participant came close to death through collapsed lungs and now lives with the aid of a respirator. When talking to his mother about this she mentioned how they were due at a young cousin's funeral the next day.

One participant recalled his experiences with ill-health, substance abuse and violence within his family, leading to tragic loss of his family members and family relationships.

I just came back from H..... I went to visit my mother who had a stroke. She'd always been a heavy drinker all her life and she was a young girl when she had us boys and one girl. One sister I haven't met yet, but the rest of the brothers I have. I think my sister might be around here in Perth. I haven't met her yet". I met my dad for the first time in 1980. He was 40 when I was 18. I was starting to get to know him. We got along pretty well. My mum and I didn't communicate much because she was a drinker and I can communicate easier with my dad. I was hoping that we could keep on getting to know each other but he passed away. He got beaten to death and left in the gutter. My aunty and I went to see him in hospital and that was just about the last time. ... I did not want to cry for my father at the funeral as I had only just met him for the first time in years. my brother beat me because I would not cry. ...one of my

brothers was lost around C..... last year. They only found his wallet. No one knows what happened to him.

This same man was concerned for the future of the younger Aboriginal population in his home area in the North West.

... some of the young people now are starting to get on the grog and the older ones have been on the grog and some of them are getting off the grog. There's been a lot of deaths in grog, almost a funeral every day of the week.

The experience of death was common also to another man, only in his late twenties, who remembers his dead "baby sister" who died as an infant, and whose parents died while he was still young.

Yeah, I had a mum and dad but they've passed on....

Loss of culture

Several participants were taken from their families to Perth because of care and medical attention being available there and not in the country.

Yeah, I think there's a lot that's missed out. At the moment I am just starting to get to know all my relations, my people. It's taken me all this time to look for them, but never mind.

I am from M..., a little town up north. My mother couldn't look after us kids so I was looked after by my grand parents in P... under Native Welfare. The school teacher in P... noticed I had an eye sight problem and I came to the B... school in Perth in 1971. I was nine when I came to Perth from P... Some of my people are Nyanga and some from Strelley station but I don't know what tribe I belong to. I was never initiated, so that's why they think of me as a boy not as an adult. I don't follow tribal ways but I'd like to learn. ...yes, my grandmother and uncle might teach me.

It was surprising to the researcher that a number of participants referred to themselves as "half-castes" and "quarter-castes", terminology the researcher would not use as it is thought of as offensive to a people who identify their Aboriginality by their shared culture, not skin colour. For one participant, his part-Aboriginal, part European heritage had caused trouble with relations with members of his tribe, and, for him, was one factor in not being included in Aboriginal culture.

Sometimes you end up muddled up and mixed up. Its like a tug-o-war; your full-blooded side, your white side.

This man, who had a visual impairment, described being ridiculed by his family.

I went to the bank and my older brother, he treats me like a child, like I'm still 13 or 12 or 11, and he started to yell and said J.... where are you and in the line-up he asked somebody, have you seen my brother, a young half-caste boy and he's cross-eyed. I felt really embarrassed in front of everybody.

A participant with quadriplegia described how he deliberately cut himself off from his Aboriginal culture in order to be protected from the impact of holding an 'open house'. He believed that his health and wider interests would have suffered if he had not done so. All the same, whether it was a combination of being rejected by others and rejecting them, in response or by design, the outcome was painful.

I think the painful bit was that nobody wanted you any more. I don't know whether that's the European part of me needing to be wanted or whether it's the Aboriginal part of me.

Some other participants did not identify a loss of culture, possibly because of their, more recently acquired, disability and where disability has not prevented individuals to live within a relatively supportive family, such as was the case for three participants.

I've got my kids, my two daughters, and my aunty who lives just down the road. She comes here every day and helps me out.

Spirituality

Five participants mentioned spiritual experiences as meaningful instances in their lives. They talked about their spiritual contacts and their need to be close to nature. In some instances, to some extent, this may perhaps have been a reflection of the few human relationships in their lives, seeking some surrogates for these relationships. The researcher does not, in saying this, wish to diminish any of the inherent value of the spiritual influences that participants felt.

It is in recognition of the possible compensatory role of some of these feelings and influences, as well as an Aboriginal attachment to the land as part of their spiritual framework, that spirituality is included as of relevance to the overall topic of loss.

When I had my leg off I was a totally different person. I was totally withdrawn into my own body and another spirit was in my body but I got it out, God came down to help with that. There are spirits that help me, as well as my sister and my brother.

I like to be close to mother nature. I feel close to the earth, mother nature is good to me.

So sometimes I get a bit lonely, then I get a bit frustrated. I'll go down to the creek and just have a quiet moment in time with myself and nature...

Another participant had some experiences while in a coma, after her car accident, wherein her then unborn baby survived. She had numerous sessions with a psychiatrist afterwards to alleviate her fears of “going mad”.

I had a family standing below me and a white light underneath them, so in other words, I was leaving the Earth to cross over and I had my family on the other side - my grandpop, my dad, an aunty and that, and my grandpop had hold of one hand and the other hand was hanging down and it was like, well, you make a choice, either you want to come up here with us or you go back down there with them. The thing that made me change my mind was the whole time I was in a coma, all I kept picturing was a baby capsule and I thought no one in our family has had a baby recently and it was like Jesus, my child must have survived and here I am letting go and saying I don't want to deal with this. It was like no, I've got to go back and see - the curiosity got the better of me - I had to see what this baby capsule was holding.

Category 3: Disability and its impact

In this category participants' offer some insight into their concept of disability and how their experiences of disability have impacted in their lives.

Concept of disability

Most participants did see themselves as having a disability. These included major, visible disabilities such as quadriplegia and amputations. The limitations that their disabilities presented were keenly felt at times.

All talked freely about their disability, and its impacts were identified as both physical and social.

I suppose the other hard thing about a disability is having someone dress you and wash you, you feel like a complete child all over again.

I cannot forget about my disability.....I lost my leg and now I'm just here with my niece, battling.

An older woman identified a disability as having very visible attributes such as the use of a wheelchair. She qualified that however by including deafness.

...mainly I suppose in the wheelchairs, things that come to mind more when you see them in the wheelchairs.

The same person commented on deafness as a disability too.

...if they cannot hear what you're saying it's got to be a disability doesn't it.

One participant, from eastern Western Australia, had only later in life realised that her multiple amputations were a disability as she had never mixed with people identified as having a disability. Having lived now in Perth for a considerable time she talks about her amputee condition as a disability and recognises it as such. When she first met people with spinal injury while in hospital she was astounded.

I've never mixed with a person with a disability so I wouldn't know how they go. I've always been with family.

I was spun out. The wheelchair people, like yourself, you know, I've never seen a person in a wheelchair. I've seen em go by but you stop and think oh gee,I've never really seen an amputee, like I say I just stick to my own sort of people and that's it and that sort of opened my eyes up, sort of thing. How they just go on living day by day.

She related that her family still did not see her as having a disability or as any different to them.

No, they don't even think like that. They just help. If I ask for help, they help me. Disability doesn't enter their heads.

This statement was interpreted to mean that, despite her disability, the family continued to see her as a loved and valued family member, not that they regarded her as not having a disability.

Impacts of disability.

Some impacts discussed here have been discussed above but it is considered relevant to give an insight into instances where the participants were very aware of particular impacts occurring in their lives because of their disability. It must be acknowledged of course that many issues are interrelated and are not always easily isolated.

Several participants described having lost friends because of the onset of disability. A man with quadriplegia gives an example of this.

Yeah, I had a 100 Aboriginal mates, I never saw one of them after I broke my neck, but I had a dozen or two white mates - they came. But I think only one Aboriginal boy I knew came to talk. Now I don't see him at all.

A number of participants were dislocated from their own country and people because of the perceived need for medical treatment and support services in the city. For instance, while still a young man with paraplegia in the South West of the state, this participant found it logistically too hard to live in the country of his birth.

There were some things that I achieved in some ways but in the country it's too tough for people in wheelchairs. The facilities aren't there; the hospitals and the chemist. They haven't got the equipment you need.

Six participants did have support from one family member only, some on an unreliable basis. As discussed some had no family support at all none at all and felt abandoned.

Some in the family do sometimes take advantage of the disability while others help. A man with intellectual disability describes this well.

I had a mum and dad but they passed on. I've got my sister. She's good to me, she look after me and take care of me sort of thing but sometime if I go on holiday she'll go back and check on this house when I'm gone. Sometimes she comes in for a yarn or a cup of tea or whatever. She's quite good. Sometimes my other sister been here before. I was on holidays and I'd just come back from my holidays and my other sister been back in my house and she broke in the back door and hocked my stereo. A couple of days later I got it back from her, from the pawn shop.She'd been locked up in X (women's prison) for a long time and the police won't let her go because they know that she stole my next door neighbour's car and took all the things away from him. She even stole his crock pot.

Sexual abuse has been reported under other sub categories but can also be considered a result of heightened vulnerability through disability. Several men with intellectual disability told of sexual abuse, by service workers, family and the public.

... I went to the toilet and one man approached me and he took my clothes off and ... and that's the reason I took a long time, I spent 20 minutes in there.

Imprisonment has also been dealt with under another category but could also be considered to be a direct impact of disability, particularly intellectual disability. These overlaps highlight the interwoven nature of the double disadvantage Aboriginal people with disability face. Several participants with intellectual disability had experience of incarceration. One man with intellectual disability described his involvement in criminal activities when a young teenager, causing him to be imprisoned.

When I was locked up, when I was 15, I was running round and breaking into people's houses, running amok and they could not handle me properly.

In prison he then found things "frightening".

Some participants expressed feeling less self-worth although others did not seem to feel this. A man described that after the amputation of his leg he had lost his sense of identity.

I didn't know who I was.

... I am just a boring person now. I used to walk everywhere.

Institutionalisation

Institutionalisation, in hostel, nursing home, hospital, or prison was a common experience for most participants. Accommodation in these places increased their vulnerability to isolation, experimentation, violence and abuse.

One participant related how, after initial hospitalisation, he was accommodated in an old person's nursing home as the only Aboriginal person from among a group of people with spinal injury who went from the hospital to the newly established nursing home for people with spinal injuries.

After my rehabilitation I ended up in a C-class hospital, the ... and there was no more rehabilitation as far as they were concerned - this was 30 years ago. I think I was just dropped out of the spinal ward... and expected to be forgotten and die. If I had got any back-up there I'd have gotten out of that place. Degrading things like being dragged through the bloody cleaning liquid on the toilet seat and being exposed to the elements and all that.....they were the most degrading things. Having to go to bed at 4 o'clock in the afternoon and get up at 10 in the morning, so you've got six hours in the wheelchair and eighteen in bed - and that's a 24 year old, it literally kills any ambitions or any spark you've got there".

After this man entered a nursing home specifically catering to those with spinal injury he found himself immersed in the medical model approach to care.

If your doctor who has just saved your life said to you, I can help you move your hand, which is something you pray for every day of your life, well - go ahead, do it. He is not going to tell you it's experimental, we're experimenting on you ... we were in a laboratory as far as I am concerned. We were all laboratory rats. That was the ... (home for spinal injured people), but coming from the ... (old persons' nursing home) to me it seemed like a nice laboratory, you know. I didn't mind being in a nice laboratory.

Some participants had been patients at a mental health hospital .

Its alright in ... (mental health hospital, locked ward). You get sick of the place after a while but when you get to know them its okay. But this was in a locked ward: there was a lot of pressure on me while I was in there, kept walking around wanting to fight everybody. And I fought one bloke there and they locked me in my room, in an empty room. And they made me sleep in that empty room with no shirt on. I went numb and I did not feel it (the cold).

Not all however found institutionalisation a bad experience. A young woman who had both arms and legs amputated at a young age:

I just went to hospital in K... when I was nine months old. I was teething and had a high temperature and after that I picked up a bug in the hospital and it stopped my circulation in my arms and legs, so they had to amputate.

She spent a lot of her days as a growing child in hospital, away from family:

I used to live in the hospital for a while, I had to wait for the legs to be made and sometimes, growing up I had to get the bone trimmed all the time. When you grow, your bone grows and it used to grow straight through my skin. So I used to spend a lot of time there. I think I had a good life there."

For others, liking hospital, appeared to be a health hazard. A participant who had indicated that he rather enjoyed the care in hospital when he had a previous leg amputation, had another leg amputated during the course of this study, apparently having neglected the care of his remaining leg. Leading up to this he had also lost the assistance of his sister and his public housing unit, having it substituted for one-room accommodation in a hostel for, mainly, people with psychiatric conditions. Did he perhaps pay a high price for care and temporary relationships?

Category 4: Knowledge and awareness of advocacy and barriers to it

In this last category participants express their knowledge of advocacy and awareness of any advocacy assistance through agencies in Perth. Barriers to advocacy are identified.

Advocacy concept

Not one participant could describe what advocacy was. Even the word advocacy was unknown. The closest appreciation of what advocacy meant came from one participant only, who could not elaborate further.

An advocate is someone who advocates something for someone else. No, I don't know what advocacy is, I know what the word means.

Some other answers to a question asking for the participants' understanding of advocacy showed a lack of knowledge.

I think I have heard of it somewhere. What one is that, is that for oldies?

I don't know anything.

I'd heard of it but I couldn't quite understand it before. I heard it on radio and TV.

On asking about participants' awareness of any disability advocacy agencies in Perth, not one participant could identify any.

Many participants had received help from various parties, other than advocacy agencies. Some of their assistance could have constituted, or included, advocacy. In response to what they would do if they required someone to speak up for them they identified family, self, a social worker, the Aboriginal Medical Service, a lawyer, their doctor and others. Two participants said they had help from a sister and a cousin who occupied a position within an Aboriginal support organisation. One had helped with public housing accommodation, the other could not really identify what the help had entailed.

Ring my lawyer or another lawyer.

My doctor always writes the letters to people and saves me doing the talking. I just tell the doctor and she writes the letter..

Yes, I've done it myself. I threatened them (Public Housing Authority). I said either you help me or I am going to an MP and I'll make sure this is known through all the local papers and if I have to I'll go to The West Australian. Within a week my plans were brought back around, showing me that I had a new ensuite.

That lady from the women's refuge I was telling you about, she helped me.

I had a cousin of mine doing time there too so we hung around together.

On a few occasions participants had initiated some action themselves. A man with visual and mild intellectual impairment told of his brother taking advantage of him in getting him to pay for the rent of a place he did not live in. He resolved that by talking to public housing authority himself.

I went to the ... people and they said no, there's no way he's allowed to charge people, he's not allowed to charge me because I'm a visitor here, he can only charge me if I agree to be with him in a certain month or whatever, if I agreed with him to share the house.

Most participants had some idea that their disability heightened their vulnerability, though perhaps not always consciously so.

...I'm a little bit slow at things but I pick things up. For instance, a person that I might not know could take advantage of me money wise.

All participants said they would use an advocacy agency, after the concept was explained to them.

Yeah, I'd go to a place like that... if I ever need any help.

None thought that it was important that Aboriginal people should be working there though they often contradicted themselves in other contexts. The most important thing to participants was that the advocates would actually be able to help them.

I don't care. No, it doesn't make any difference to me, I'll just see how smart they are.

You shouldn't be judged on your colour, creed or race. You should be judged as a human being because that's what people are. I am sure if someone grabbed a knife and cut your arm and then cut mine and held them up together, we'd have the same colour blood, so why should skin colour, race or religion have anything to do with it?

It would help if there were Aboriginal people in certain places.

It all depends on who they are and what they are. People are people to me, white or black, it doesn't matter to me.

This same, last participant also spoke of not staying in a particular hostel because there were no Aboriginal workers there, contradicting himself.

The seeming contradiction between not needing Aboriginal workers in advocacy agencies but saying the opposite for other situations, may have been due to expressing, to a white interviewer, their feelings about equality regardless of skin colour. It may have been less a response to a question about the desirability of having Aboriginal workers in advocacy agencies so as to make Aboriginal people who use advocacy feel more at ease.

Family feuds and cultural differences

Many participants referred to family feuds as a barrier to using any advocacy agency they might visit if a member of an Aboriginal family they were feuding with was working there.

That's the problem with the system, it's not what you know, it's who you know. If someone's fighting with a member in your family and you go in there and say I'm (name) , the person says ohh....

... I reckon if that family member knows you're fighting with the opposite side of the family I reckon they could upset your case a lot.

Several described how they were involved in such family fights at present, typified by the statement of one participant:

At the moment with my Mum's family and all this land stuff that's going on there, it's torn the family three ways. My Mum's older brother is fighting against her older sister because her older sister is actually married to a X which is another family up there and my uncle is a Y and the Y's and the X's aren't talking because my mother is a Y. If we go up there it's like because my aunty is married to an X and they're fighting against the Y's, she won't even say hello to us in the shop. It's like well that's stupid, because we are your family. She won't even acknowledge her own sister. She walked straight past Mum and Mum is totally hurt because she's the youngest out of the family and with her brothers and sisters fighting like that and taking it out on her - doing the land thing with them, she's not taking sides, she's just a neutral member of the family who's quite happy to go up there and listen to what's going on and I've got cousins down here I don't even see or hear of. Yeah, the families are fighting so if one member is fighting against another, you don't have anything to do with them.

Yet other participants said they had no trouble with family:

I wouldn't have a clue. I've never lived that way. I've always lived here in Perth so I know a bit more of Nyoongar way more than I do my own way (Wongi).. I lived with a Nyoongar family after I came here before I got into my house.

Whereas all participants said they themselves had no difficulty in using an advocacy agency where only white people worked, one expressed a view on behalf of other Aboriginal people which contradicted this. He also identified differences between tribes, reflected by responses of some other participants, whereas others did not.

You've got to be able to walk into somebody's place and be accepted. The minute you get out of your car in front of an Aboriginal home and you're white, there's automatically a barrier goes up. It doesn't matter if you go there a hundred times, they automatically change. The household changes completely. I think with Aboriginal people you're going to get a clash of ... like there are groups of us and we all know each others names and those names belong to tribes. Now those tribes, whether you like it or not, have been arguing with each other since time began, so say if the A's were fighting and the D's were fighting you wouldn't send an A to a D's house to be an advocate. So you're going to have to understand if you're going to teach these people, that they'll have to be told where they're going and be allowed to say, well I cannot really go there because I'm not of their skin or whatever they are.

They're the same, Wongi, Nyoongar, all the same, it's only different tribal names.

Shame and shyness

After some explanation what an advocacy agency might be able to do and when reflecting on whether they would use an advocacy agency in the future, shame and shyness was often mentioned.

If it was a big building with a lot of people, that would put me off. I just like things to be a little size, you know, when you come from the country, there's only just a little bit of people. I get nervous walking the city, that's why I don't go there much. I think it's just the crowd, I'm frightened they might bump me and I'll fall over or something. If I was to go to that place like you said, I'd take M..., or Y., one of the workers (of an Aboriginal support service).

More or less, you're ashamed to tell your story or what it's about or something. But there comes a time when you've got to open up if you want the full help.

I wouldn't know how to contact them.

The words 'shame' and 'shy' seem interchangeable in the way participants used it. Many participants expressed a sense of "shame" or "shyness" in various contexts. Some used it in discussing their involvement in the interview, whether they would use an advocacy group or about being involved in the interview for this research.

Yeah, that's why I said to M... (worker from Aboriginal support service); can you come and sit with me, I was a bit shy, ashamed sort of thing you know, but when I explained it to my auntie she said, no, tell him to come around, ... so she encouraged me to sit here with you.

When I am with whites I get a bit shamed and nervous. When I am in my own house I can talk

A thread common to most interviews was that the participants, both male and female, expressed that once they were shy, but now no longer, and they liked to speak up for themselves. There was this expression of past shyness while appearing to confidently tell the researcher about very personal things.

I like to speak up for myself. If I know something's not right - I'm forward now. I've been like this for the last eight years, before that I was shy as anything.

...I like outdoor activities even though, in a way, I'm still shy about people. I like someone that's interested in books. Sometimes when I see people in trains or buses reading a book I just have an urge to talk to them.

At the same time the man owning this last quote, significantly vision-impaired, said that when in the city:

I seem to get along with strangers. I say 'good morning'. They say 'good morning' back. Some of them..., some of them I guess they wish they were still in bed so they could sleep instead of getting up in the morning to go to work. I don't really have much problem with strangers.

Another participant put it this way:

If a person like yourself comes to the house I don't mind but if I've got to go out ... I wouldn't talk in front of a big mob, no way.

Shyness and 'shame' is a typical Aboriginal expression. It does not mean that people are ashamed about their disability. A participant with amputations to four limbs said:

Shy, shame, same thing. It does not mean that I am ashamed of the disability.

By contrast a participant with quadriplegia, the only participant to do so, explained her shyness as caused by the newly acquired disability, rather than to any Aboriginal feeling of 'shame'.

...I've only been in a chair for a year. I still have these anxiety attacks. If I go out and there's a whole crowd of people, I've got to get in the open air.

This same woman related many actions she initiated and followed through in getting public housing to co-operate, "educating" rude shop keepers, contacting the Shire about accessible foot paths and more. Shyness then, is not universally felt or easily understood.

Discussion of results.

The purpose of this study was to find the reasons for an apparent low use of advocacy agencies in Perth by Aboriginal and Torres Strait Islander people who have a disability, in a context of higher than average disability rates for this population. The results are discussed within the framework provided by the

objectives of this study, with reference to the literature explored in Chapter 2.

For purpose of triangulation the results are then discussed within the framework of wounding (Wolfensberger, 1987).

Objectives for the study were:

1. To identify influences and barriers to the use of disability advocacy agencies in Perth by Aboriginal people with disability and their families.
2. To establish an indication of use of disability advocacy agencies in Perth by Aboriginal people with disability and their families.
3. To identify a common Aboriginal concept of 'need for advocacy'.
4. To identify the actions Aboriginal people with disabilities and their families take when in need of disability advocacy.

Objective 1. To identify influences and barriers to the use of disability advocacy agencies in Perth by Aboriginal people with disability and their families

None of the participants had any awareness of the nature of advocacy or any knowledge of any existing disability advocacy agencies in Perth,

confirming findings by Gething (1995), O'Neill, (1993), Smeaton (1996) and Wolstenholme (1996) in disability support services.

This lack of awareness could partially be explained by a lack of information about assistance through any advocacy agencies. The finding of low overall representation of Aboriginal people who received advocacy (advocates) in Perth advocacy agencies confirms the findings of Cross and Zeni (1993). Because the participants, in getting any assistance, relied on people such as family, themselves, a social worker, an Aboriginal health service, a lawyer, their doctor and others, this low awareness also reflects on the levels of awareness of advocacy in Perth by such individuals and agencies. In the general community then, it seems, advocacy is not well known, presenting a barrier to its use.

There are four other possible factors in explaining this low representation. First, it would not always be in the interest of a disability service agency to refer a service user to an advocacy agency as the advocacy may be directed against it. Second advocacy agencies are always trying to cope with a much greater need than they are equipped to meet (Cocks & Duffy, 1993) and, where there is a higher awareness of advocacy among non-Aboriginal people with a disability who take up scarce advocacy resources, there may simply be little scope left to advocate for other groups of vulnerable people. Third, most advocacy agencies may not actively seek out vulnerable people who need advocacy, but wait for referrals and advocates to contact them, whereas Aboriginal people do not

know where to go for help. Fourth, many advocacy agencies may be more formal than informal in their advocacy processes whereas Aboriginal people prefer an informal, personal approach (Gething, 1994; Gething et al, 1994).

Gething (1994) and Gething et al, 1994 commented on the low awareness among Aboriginal people of their rights, of available services or about how to gain access to them. The difference between Gething's findings for general disability support services and this study is that, where the Australian community is probably reasonably aware of general disability support services, at least some sections of the community appear almost completely unaware of advocacy and of any help available through advocacy agencies. Advocacy, in comparison to the disability service system has a very low profile. This means that whereas the service system may at least identify some Aboriginal people in need of their services through referral by doctors, social workers and so forth, this is not the case with advocacy.

Citizen Advocacy agencies by nature (O'Brien & Wolfensberger, 1978) rely on informal ways to identify people in need of advocacy, rather than necessarily relying on referrals or advocates coming to them. As informal means of disseminating information, among Aboriginal people, such as 'word-of-mouth' is considered best (Gething, 1994), this may account for some of the relative success of such agencies in Perth with regards to advocacy for Aboriginal people with disability in need of advocacy. It is confirmation also of the appropriateness of this study's methodology which provides for capturing the

essences of participants' experiences and allowing representation of the data in their own words.

Most participants said they would have used disability advocacy agencies if they had known about them or would use them now, if needed. Various obstacles to their future use of these agencies include the probable lack of Aboriginal workers in advocacy agencies; preferring to avoid the city where many assumed these agencies were; shyness about approaching people they did not know, particularly if not on a one-to-one basis; and experience of past inaction on their behalf when they did ask somebody for help. These barriers are also present where it concerns Aboriginal access to general disability support services (Gething, 1994; Gething et al, 1994; O'Neill, 1993 and Smeaton, 1997).

The enormity and frequency of the negative experiences most participants had had, and were continuing to experience, point, at the same time, to the great need for advocacy as well as to barriers to advocacy. Many of the participants experienced rejection by society and family; losing close relationships; were ignored when very vulnerable and abused; had their lives wasted by waiting for employment or accommodation that never came; have reduced educational and employment opportunities; have ill-health, violence and death as a constant companion; have been excluded from their cultural and spiritual heritage; and fell between an Aboriginal and a non-Aboriginal world, causing alienation. These findings confirm similar findings by Bostock (1991),

Gething (1995), Wilson (1997), Wolstenholme (1996) and Smallwood, White & Kotiw (1997). When, on top of that, one considers the Aboriginal lack of political power, their poverty, their relatively low status as both an Aboriginal person and person with disability (Bostock, 1991; O'Neill, 1993), one can understand why such people did not access an advocacy agency, even if they knew about it. Some participants showed a loss of self esteem, explainable by their past experiences, and this does not promote the acquisition of confidence and social skills needed to make personal contact with any agency. If no one will refer them to advocacy it is also not likely that, under current conditions, they will refer themselves either.

The reluctance, demonstrated by most participants, to complain presents an additional barrier for Aboriginal access to advocacy, particularly advocacy which relied on the advocate bringing their issues to them.

The broader context is another barrier to accessing advocacy as disability is only one small issue within many Aboriginal problems, as shown by the participants' responses. Disability issues may simply not get the priority needed to bring them to anyone's attention, and may partly explain participants' ambivalence about their need for advocacy. Participants in this study did not identify disability related issues that they thought they needed advocacy for, although such issues were clearly present. Bostock (1991), Gething (1995) and O'Neill (1993) confirm this low priority of disability issues among Aboriginal people.

Distrust of service providers is raised in the literature as a significant barrier to accessing disability services (Gething, 1994, O'Neill, 1993). The participants in this study confirmed those findings but also indicated their willingness to access advocacy once they knew how to contact it. Two received advocacy after being put in touch with an advocacy agency during the study. It may confirm that the personal approach by an interviewer who came to them and visibly shared their experience of disability can make a difference. Distrust centred round the competency of advocacy agencies and on not being let down again, rather than of an agency per se. No negative associations with government agencies were made, as could be expected from the impacts of past government policies on Aboriginal people (Wilson, 1997). This does not mean that they were not present; they may have been, but they were not expressed.

Although all participants said they were willing to access advocacy if they needed it in future, their past experiences of inaction by individuals and service agencies had caused many of them to have low expectations of any service organisation or professionals. For some, this has not only resulted in a level of scepticism of anyone acting on their behalf, but also in a level of acceptance of such low standards and an attendant low level of initiative of participants to ask for help themselves.

Any advocacy agencies seeking to reach Aboriginal people may need to address this distrust and low expectations by, for instance, creating a good

advocacy track record that creates a level of trust and standing among Aboriginal communities.

Many participants contradicted themselves when they indicated they did not need Aboriginal workers in advocacy agencies but, in other contexts, freely pointed to the desirability of an Aboriginal presence to make them feel more comfortable. This mixed response was thought to be due to their reaction to a white interviewer asking, in their view, a question about inequality between Aboriginal and non-Aboriginal people. They did not make a distinction between the need for an Aboriginal presence in advocacy agencies versus other support. The conclusion the researcher has drawn is that a presence of Aboriginal workers in advocacy agencies is important to them. Gething (1994), Gething et al (1994), O'Neill (1993) and Smeaton (1997) have all found this to be the case in studies of service agencies. This has to be qualified by the participants' insistence on competent advocacy as very important, regardless of who does it.

Having Aboriginal workers in advocacy agencies however is not the straightforward remedy it appears. This explains the participants' insistence on the importance of competent advocacy over the presence of Aboriginal workers. Difficulties between Aboriginal families and various tribal groups could cause an advocate from an opposing 'camp' to the advocacy agency's Aboriginal worker's family to receive assistance which contains an inherent and significant conflict of interest. The advocate may not get the help they need or

get no help at all. This does not mean that Aboriginal workers should not be employed. Rather, at the very least, the employing agency and its workers should be aware of this issue so that any conflicts of interest can be declared and alternative means of proceeding are sought.

Not all advocacy agencies reside in the city, although two of the surveyed agencies do. There are barriers to their access due to an Aboriginal shyness of crowds and strangers and the necessary transport expense which may be prohibitive for people who live in poverty. Other agencies are dispersed over the Perth Metropolitan area and transport to them would play a role there too, as well as shyness with strangers. Even telephonic contact from a potential advocate to an advocacy agency is sometimes not possible as the phone may not be connected due to inability to pay telephone bills.

This study did not find that Aboriginal people have a different perception of disability, which Gething (1994), Gething et al (1994) and O'Neill (1993) do point to as an additional barrier to access support. This study was done in a city, where disability is usually accepted to apply to a wide range of conditions, including physical, intellectual, psychiatric and sensory impairments, from mild to severe. The participants mostly had long-term experience of the Perth medical and disability support services. Consequently, they had been exposed to, and had adopted, Australian mainstream ideas of disability, rather than any Aboriginal view. Only one participant had had a short-term experience of disability (one year) but her long term metropolitan status and severity of

disability, being quadriplegia, meant, she had also accepted her condition as constituting a disability.

Another participant with multiple amputations said that her family, from a remote area, saw her as no different or treated her any different but she did herself recognise a disability. This did not mean of course that her family did not recognise her limitations as. Nor can the conclusion be drawn that theirs is a typically Aboriginal attitude towards someone with a disability. Perhaps it was simply their attitude. Disability is seen through a specifically Aboriginal lense in some rural areas and remote areas (Gething, 1994; Gething et al, 1994; Bostock, 1991; Smeaton, 1997) but this is different in a city like Perth where the interviewees had lived for a considerable time.

Therefore, it may be important for advocacy agencies to realise that they should be careful about adopting any conventional wisdom about a specifically Aboriginal concept of disability, especially here in Perth. Should they proceed with an exclusive notion that Aboriginal people may, for instance, not recognise certain impairments as disability, they may put a different perspective on any need for advocacy, based on a cultural understanding that is not appropriate. This issue relates to service provider assumptions that Aboriginal people look after their own, causing them not to be sought out for help by services as shown by Smeaton (1997). As this study has shown, family can abandon and harm Aboriginal people with disabilities as well as play a supporting role.

On the whole, these findings mostly do not confirm the researcher's original conjecture that reasons for low Aboriginal access to support services may not be the same as for low access rates to advocacy agencies. There are some differences, but not substantial ones. The participants' perception of disability was, for instance, not found to be different to the mainstream idea of disability and consequently was found to be not a barrier. Aboriginal workers are important but should be cautiously employed due to family feuds. The only other difference is in the degree to which services and advocacy may be known to Aboriginal people. Where this is low for services, for advocacy it is non-existent.

**Objective 2. To establish an indication of use of disability
advocacy agencies in Perth by Aboriginal people with disability
and their families**

This objective has been explored and discussed in Chapter Two.

**Objective 3. To identify a common Aboriginal concept of 'need
for advocacy'**

Advocacy is a Western framework to address discrimination, abuse and inequality. The word 'advocacy' derives from 'advocat' in French or 'advocaat' in Dutch, where the word means 'lawyer'. Lawyers often ply their trade in an

adversarial manner. Some disability advocacy is conducted in this manner from time to time but differs from law work in that it seeks to represent the genuinely perceived best interests of a person or group that requires advocacy. At times, this approach requires the advocate to act against the wishes of the advocatee as wishes and best interest are not always synonymous. Lawyers generally are briefed by their clients and act on their wishes. One could not assume that advocacy, as conceptualised in this study, would necessarily apply to Aboriginal people who have a cultural background which is very different to the Western perspective.

The participants related very serious issues of disadvantage and abuse, yet referred to relatively minor issues when asked whether they needed or had ever needed any help in the form of advocacy. Some said they had no issues to be addressed, which could be related to the identified reluctance to complain. It seemed that the wider, and more serious, Aboriginal context was, to a degree, accepted as inevitable and, perhaps even, as a norm that one could do little about. Some of the reasons for this have been discussed.

Most of the issues that were identified in this study, for which advocacy might be needed on behalf of Aboriginal people with disability, would probably not have existed before the arrival of the now dominant Western culture.

As shown, dislocation and loss of family, loss of culture, health problems, substance abuse, incarceration, material poverty, institutionalisation, murder and violence are some of the underlying issues that magnify the vulnerability participants experience by nature of their disabilities alone. They are issues arising from the Aboriginal position in Australian society, imposed by a culture which has not accepted or valued Aboriginal culture. This would include a loss of connection to their land, signified by participants in this study by their expressions of spirituality and closeness to 'Mother Nature'. O'Neill (1993) and Gething et al (1994) confirm the importance of the close Aboriginal connection to the land in this context.

Many of the issues that call for advocacy, being a result of tension between the two cultures, are not uniquely Aboriginal, in a cultural or traditional sense. Rather, they are, in the main, defined by the experiences of ill-treatment and disadvantage that Aboriginal people have suffered, as individuals, and as a collective. They are the magnified issues that are common throughout Western societies, be it at much lower levels than is true for Aboriginal people. This uniquely Aboriginal context is strongly influenced by the extraordinarily high rates of disadvantage among them. There are of course specific Aboriginal discriminatory circumstances, culture and history to take into account when doing advocacy with them or on their behalf but the issues of abuse, neglect and isolation are well known to disability advocates as universal experiences of people with disabilities (Cocks & Duffy, 1993; Cross & Zeni, 1993; Wolfensberger, 1992, 1987). There seems no reason therefore why advocacy, as

defined for this study, cannot become more responsive to the specific needs of Aboriginal people.

There is no typical Aboriginal approach to protecting people from abuse and neglect or to meet their needs. They mostly use people that are at hand and are familiar to them, like family, professionals, lawyers from the Aboriginal Legal Service and social workers. Apart from family, of course, these parties are all linked to the Western system and culture. Yet Aboriginal people do use these people, imperfect as the result may be. Issues of shame, shyness and feelings of powerlessness make it difficult for many Aboriginal families to advocate effectively. These issues mean that, in most instances, they have little standing or status to impress those parties against whom advocacy needs to be employed.

The participants, in this study, were most interested in whether the advocates would be able to help them, as one participant with brain damage put it: "see how smart they are". It seems that advocates are required who are both close to the realities of Aboriginal life, and who are effective in achieving positive change. This signifies that to be a disability advocate for Aboriginal people, it includes working with the larger issues of loss of family, culture and relationships as well as immediate problems related to disability.

Several participants felt they were alienated from both Aboriginal and non-Aboriginal society, and experienced a loss of Aboriginal culture, because of

their mixed heritage. This is no isolated picture, specific to this small sample but has been identified in the 'Stolen Children' report (Wilson, 1997) as being widespread. Under these circumstances they are not able to link into either 'world' for any informal support and could not use any traditional Aboriginal ways of protecting vulnerable people, if these existed. At the same time these people, who have fallen between the two cultures, are among the most vulnerable among the very vulnerable! They are among those most in need of advocacy.

In summary, if there is a concept of "need for advocacy" that could be called Aboriginal, it is one where disability issues requiring advocacy are overshadowed by the wider Aboriginal context of great disadvantage and abuse where action is often seen as futile. This study did not identify any cultural Aboriginal ways to describe or deal with a need for advocacy but did find that the context for Aboriginal people with disability is unique in terms of the enormity and number of broader issues they carry. Advocates would need to be fully aware of this wider context and work within it. Bridgman (1992), at least in part, confirms this when he points to the need for advocacy agencies to adopt culture-specific practices.

Objective 4. To identify the actions Aboriginal people with disabilities and their families take when in need of disability advocacy

The participants in this study relied on self, family, doctors, lawyers from the Aboriginal Legal Service, social workers and other community service workers, including an Aboriginal health service. They sought to address issues from accommodation, sexual abuse, employment, bill paying to obtaining a garden shed. Often the issues were identified and progressed by a casual helper rather than issues being purposefully brought to their attention by the participants. Two participants were successful in getting some issues resolved with the public housing authority but others were not successful in getting anything done about their complaints or requests. Family could not always help as they were, at times, the antagonists or were not present.

Shyness, loss of confidence in getting meaningful, "smart", assistance; acceptance of circumstances; lack of information on where to go; and lack of transport and telephone if they had had information, meant that mostly little action was taken.

It would seem that any advocacy effort would not only need to be culturally and historically aware of Aboriginal circumstances, but needs to go and find Aboriginal people with disabilities, talk with them and establish a

track record of mutual trust based on meeting real need. Any advocacy which would purely rely on people coming to them will never address the Aboriginal need.

The findings in the light of Social Role Valorization theory of 'wounding'

Social Role Valorization theory (Wolfensberger, 1987, 1992) incorporates the key concept of a series of wounds which are often present in people that belong to groups that society sees as of lesser value. People with disabilities are one such group, with wounds being particularly manifest in extra vulnerable people with disabilities. These are shown in Appendix E.

Wolfensberger (1987, 1992) explained these wounds as arising from the devalued position that people with disability occupy in our contemporary society. They often embody the opposite values that society as a whole does see as desirable. For instance many people with disability do not conform to the valued images of youthful health and well being or material wealth. These people are then seen by others as of lesser worth than them. They will treat people according to this negative perception and deny them the things which valued people enjoy, including good quality housing, education and employment. They will reject, segregate and exclude devalued people from

society and community. The bad things that happen to people as a result of their devaluation are the wounds they carry.

Wolfensberger (1987) has identified these as universal negative experiences of devalued people. Most of these wounds were present in the participants, confirming their universality. The Aboriginal context does not alter the relevance of these wounds, which affirms the finding that it is the universal context of abuse, violence, neglect and discrimination which provides the background to the advocacy needs of Aboriginal people with disability. This background is not synonymous with Aboriginal culture but with the general, unfortunate circumstances of Aboriginal people in this country. They are common problems in our society, magnified greatly in the lives of Aboriginal people. The added layer of disability magnifies these problems further still.

We can identify a downward spiral where, in the life of an Aboriginal person with disability, the Aboriginal health, substance abuse and violence issues may have been the cause of the disability (wound 1) and continue to worsen the disability and the person's functionality (wound 2). The disability leads to an even lower status (wound 3) than is already the case by belonging to a devalued ethnic group (wound 12). Rejection by family and community (wound 4) leads to loss of relationships with family (wounds 6, 8) and culture (wound 7), including its spiritual core (13). It can also lead to being removed from one's home country (wounds 7, 9), for reason of medical attention or

support service availability elsewhere. We have seen that people can wait endlessly for services or for redress (wound 14) for abuse in the service system or elsewhere (wound 17) and can be eloquently aware of being an alien in this world (wound 18) as they lost culture, family and relationships (wounds 6, 8, 12). Family ridicule (wound 4) and material poverty (wound 11) are additional experiences which almost pale in significance against the overwhelming nature and frequency of negative experiences.

Oliver (1996) would reject the notion that these experiences are carried as wounds by individuals and says that it is society which caused the disability by inflicting these experiences. There is no doubt however that participants keenly felt issues such as separation from family and culture and past abuse and carried these as unwelcome memories, or wounds, in their psyche.

Whereas one could easily argue that in reality both views have a degree of merit and can be seen as complementary, the wounding approach implies the crucial notion of heightened vulnerability of people with disability, ignored by Oliver (1996), who relies on societal attitudinal change as a remedy to disability. The relevance of the wounding theory to advocacy is the recognition that highly vulnerable people need protection and a heightened vulnerability for people with a disability will always be relevant in any society. Oliver's (1996) social model may seek change while ignoring this protective need for individuals, not recognising this vulnerability. As a result, his model also does

not take into account that vulnerability of people with disability, and other groups, will very likely be present in any society, including reformed ones.

Wolfensberger's (1987) approach does recognise the inherent vulnerability of people with disabilities. Aboriginal people with disability would be best served with approaches which recognise the need for ongoing protection as well as attitudinal change. This would lead to the development of multiple forms of advocacy with various emphases, according to need.

One notable wound that was not apparent in the participants was "resentment, hatred of privileged citizens" (Wolfensberger, 1987, p. 11). In view of the long sufferance of Aboriginal people in this country without the advent of major riots or upheavals, such as for instance the African-American minority staged in the United States of America in the sixties and seventies, one wonders whether there is something about the Aboriginal culture which makes resentment and hatred alien to it. Not one participant expressed such feelings.

As well as authenticating the participants' experiences of gross devaluation these wounds also confirm some reasons for not accessing advocacy that were identified from the interviews.

People with a disability who have been rejected (wound 4) are not likely to feel confident enough (wound 18) to seek help, even if their disability (wounds 1, 2) itself would not present a barrier to do so. This wound 18 then, of

personal insecurity and self-dislike, throws further light on Aboriginal “shyness and shame” as very likely being influenced by this low self-esteem, rather than being a purely Aboriginal concept in the context of this study.

People in poverty (wound 11) cannot afford the phone bill or transport to get to an agency, again confirming the findings.

The primary reason for not using advocacy, that of not knowing of its existence, could be explained, in part at least, by the participants’ experience of discontinuity of social and relationships (wound 6). It can be further explained by their loss of control over their personal circumstances, feeling an alien in this world, and by their exclusion from the valued world (wounds 9,18,12). These experiences would lead to a lessening of opportunities to receive information about advocacy.

The wounds model largely confirms the findings of this study, in particular the universal nature of these negative experiences in the lives of people with disabilities. It also presents confirmation of many of the reasons, found in this study, for reasons why Aboriginal people with disabilities do not freely access advocacy agencies. The validity of the results are therefore confirmed.

CHAPTER SIX

CONCLUSION AND IMPLICATIONS OF THIS STUDY.

This study demonstrates that there is a low use of advocacy agencies by Aboriginal people in Perth, but that this pattern is confined to advocacy forms other than Citizen Advocacy.

The primary reason for a low Aboriginal access rate of advocacy agencies in Perth, for the participants in this study, is due to an almost complete lack of knowledge among Aboriginal people of disability advocacy agencies.

Secondary issues became almost hypothetical for the participants as they did not know what advocacy was, where advocacy agencies were or how to contact them. Consequently they had never had contact with any.

However, Aboriginal shyness and loss of self-esteem; a reluctance to complain; poverty; need for Aboriginal advocacy workers; distrust of the competence of support agencies in getting things done and not identifying disability issues as important, were found to provide additional barriers to any Aboriginal use of advocacy.

There is no Aboriginal conceptualisation of advocacy and caution must be applied in assuming that Aboriginal people will "look after their own" due to

family networks. Those who need advocacy most, tend not to have any such networks and any family and communities can play the role of antagonist.

The findings of this study do not support the appropriateness of unpaid, informal advocacy for Aboriginal people with disabilities, excluding the Citizen Advocacy model. The low standing of Aboriginal people in our society, conflicts between Aboriginal groups and family as antagonists, would seem to make such informal advocacy problematic. This is not to say that effective Aboriginal, informal advocacy would not exist elsewhere or that such efforts could not be supported. Further work, with other groups of Aboriginal people, should be done on this issue.

The situation of Aboriginal people is unique, mainly because of the extreme vulnerability many of them live with. Disability merely adds another layer which can become seen as relatively unimportant by Aboriginal people, including by those who themselves have the disabilities.

In essence the various identified issues are not different to what disability advocacy agencies are used to but the Aboriginal cultural and historical background of deprivation and discrimination is inseparable from the disability issues of Aboriginal people. Some of the most vulnerable among Aboriginal people with a disability have lost their culture and family and their history of this must be understood by advocates. The paradox is that other issues often

overshadow disability issues but cannot be seen in isolation of each other if any advocacy is to be effective.

Importantly, Aboriginal people with disability are willing to use disability advocacy agencies and there seems no reason why advocacy agencies could not address the barriers to their access. However, it would not be appropriate to merely inform Aboriginal people of the existence of disability advocacy agencies without addressing the additional issues that provide barriers to Aboriginal use of these agencies.

Further work is needed to develop advocacy models that take the Aboriginal access issues into account, using the barriers identified in this study. The apparent suitability to Aboriginal people, of Citizen Advocacy, should be further investigated and improved, if possible, in the light of these findings. The principles and practices used by Citizen Advocacy should be explored for their possible adoption, entirely or in part, to other forms of advocacy, in order to improve their Aboriginal accessibility. Another benefit of such work may include a higher standard of advocacy for all vulnerable people with a disability as the most relevant issues have been shown to be universal.

At the same time, care must be taken not to adopt a “one-shoe-fits-all” approach to any development of advocacy which has improved Aboriginal access. As shown, there is a difference between rural and city environments in how Aboriginal people view disability and there may be other differences,

influenced by this environment factor. Advocacy which is able to protect and advance the position of vulnerable Aboriginal people with disability and addresses societal change is needed. However, an exclusive “rights” approach to advocacy would not suit Aboriginal people as they are private people who are reluctant to complain. The success of advocacy incorporating Aboriginal access, whether for new or existing advocacy efforts, depends on the flexibility with which the barriers are addressed. Local need, city or rural environment, community energy and leadership would need careful assessment and development in order for trust to be created. Some time must be allowed for such processes to take place.

Multiple forms of advocacy are needed to address the situation of Aboriginal people with disabilities, to suit local nuances in need and approach. Individual advocacy, Citizen Advocacy and systemic advocacy are all relevant in addressing the Aboriginal disability issues. The important role systemic advocacy could play should not be ignored in the light of the wider and many, grave Aboriginal and disability issues that are connected to personal experiences and abuses.

The definition of advocacy, adopted by this study, is especially useful to provide a framework in the development of advocacy with greater Aboriginal access. In particular its elements of “sincerely perceived interests” of the person with the disability; attention to conflict of interest and vigour address directly some of the barriers to Aboriginal use of advocacy. Whereas advocacy

would need a level of trust and acceptance from the Aboriginal community in order for it to work, the exclusive focus of advocacy should be clearly on the vulnerable person with disability. As shown in this study, family and carers can be the antagonists.

A longer-term implication of this study and any subsequent studies in developing Aboriginal-friendly advocacy models is the lack of adequate funding of advocacy agencies. A large potential number of Aboriginal advocates could not use existing advocacy agencies, given the same current resources. The larger issues of adequate funding for existing and new advocacy therefore, must be addressed when, or before, implementing any measures to increase Aboriginal access to advocacy.

In keeping with the findings of this study, such further work must be done in participation with Aboriginal people and their communities. 'Ownership', acceptance and knowledge of disability advocacy agencies that are accessible to Aboriginal people may overcome distrust of yet another agency, increase the likelihood of informal approaches and avoid the funding of any 'white elephants'.

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Appendix A.

Draft Interview Guide

The following themes will be explored. The guide shows some possible draft questions under each theme, depending on the individual's responses:

Describing the individual experience of disability and impact on their lives.

When you have a disability, sometimes it is hard to get things done for yourself because people forget you have needs too. Is it hard to forget about any bad things that have happened to you?

Describing incidents where abuse, discrimination or exclusion occurred and it would have been helpful if somebody had stood by them or somebody actually did stand by them as an advocate.

Can you remember some of the bad things that have happened to you?

Would it have been good if anyone had helped you?

Did anyone?

Describing what it is they did in such a situation.

What did you do to solve the problem and get what you wanted?

How did you feel when you did this?

Who helped you with this?

Describing their understanding of nature and purpose of advocacy.

Can you tell me what advocates do?

Describing their understanding of when advocacy is needed.

Tell me about a time when you wished you had someone to speak for you and help you?

Describing their understanding of what advocacy might be able to do.

If you knew there were people who could assist you with problems what should they be doing to be useful to you?

How would it make any difference to you in your life if you could get an advocate?

Describing their experience with any advocacy agencies in Perth.

Tell me, have you used a disability advocacy service in Perth?

What happened when you used them?

Describing any barriers to their use of disability advocacy agencies in Perth.

What sort of things would stop you from using an advocacy service?

Some demographic questions on age, gender, disability, postcode.

Appendix B.

Survey questions for agencies

How many Aboriginal people contacted your agency for advocacy between 1st July 1993 and 30th June, 1996 ?

How many Aboriginal people received advocacy from your agency between 1st July, 1993 and 30th June 1996?

How do you identify Aboriginal people who access your agency?

How many non-Aboriginal people contacted your agency for advocacy between 1st July, 1993 and 30th June 1996?

How many non-Aboriginal people received advocacy from your agency between 1st July, 1993 and 30th June, 1996?

Survey questions for Perth disability advocacy agencies

Thank you for completing this survey. I am very aware of the pressures on your time and therefore I genuinely appreciate your effort to participate.

Please use as many words and pages as you need to answer the below five questions.

I have provided a stamped, self-addressed envelope for your use in returning the survey to me. I'd be grateful for your response by or before 27th February, 1998.

Thank you again.

Sincerely,

Erik Leipoldt

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

9th January, 1998.

Citizen Advocacy groups may prefer the following questions to the standard questions. Please use these if you think them more appropriate.

1. How many Aboriginal people with disability, in need of a citizen advocate, did you identify and/or list between 1st July 1992 and 30th June, 1997?
2. How many Aboriginal people entered into an advocacy relationship through your agency between 1st July, 1992 and 30th June 1997?
3. How do you identify the aboriginality of people with disability who use your agency?
4. How many non-Aboriginal people, in need of citizen advocacy, did you identify and/or list between 1st July, 1992 and 30th June 1997?
5. How many non-Aboriginal people with disability entered into an advocacy relationship through your agency between 1st July, 1992 and 30th June, 1997?

APPENDIX C.

Letter to disability advocacy agencies

Dear.....,

**Advocacy research: Project title: "Australian Aboriginal people with disability
and their use of advocacy: A phenomenological inquiry".**

I am currently researching a thesis as part of requirements for a Bachelor of Social Science (Honours) degree in Human Services at Edith Cowan University. I am seeking your co-operation in completing a small questionnaire. Its purpose is to establish some factual insight into the incidence at which Aboriginal people with disability may use Perth disability advocacy agencies. This information will then be used to put into context the stories of the interviewees. Their stories form the major part of this study, the questionnaire is the tool for a small supporting study only.

Some seven Perth advocacy agencies will be asked to complete this questionnaire.

The overall purpose of this research is to find why it is that Aboriginal people with disability appear not to be using disability advocacy agencies in Perth. This seems an important question as it is known that Aboriginal and Torres Strait Islander people have higher levels of disability compared to the general population.

Through interviews, I aim to collect the feelings, stories and thoughts about this directly from Aboriginal people with disability, where appropriate. I hope that what I

find out by doing this research will help advocates and government funders to better understand this situation, so that appropriate ways of doing advocacy for Aboriginal people may be found.

Responses to the questionnaire will be kept in a safe location for five years, accessible to the researcher only, and will then be destroyed. Records will only be used for the purpose of this study. You are of course at liberty to decline your co-operation and should this be your decision, it would be respected with no further questions asked. Individual agencies will not be identified in the final report and any quotations of what anybody wrote will remain anonymous. The information may be published and the participation of advocacy agencies will be acknowledged unless agencies indicate otherwise.

I enclose the questionnaire to which I would appreciate your response by or before
27th February, 1998.

Thank you for considering my request. I would be pleased to discuss with you any further questions you may have about this research. You may contact me on [REDACTED]

[REDACTED]

Sincerely,

Erik Leipoldt

[REDACTED]

[REDACTED]

9th January, 1998

APPENDIX D.

Consent form

Edith Cowan University

Faculty of Health and Human Sciences

Project title: Australian Aboriginal people with disability and their use of advocacy.

Researcher: Erik Leipoldt, phone and fax (h/w) [REDACTED]

I am doing this research as part of a Bachelor of Social Science (Honours) degree in Human Services at Edith Cowan University. I also have a personal interest both through having experience of disability myself (I use a wheelchair) as well as being involved in disability advocacy for some 15 years.

The purpose of this research is to find why it is that Aboriginal people with disability appear not to be using disability advocacy agencies in Perth. This seems an important question as it is known that Aboriginal and Torres Strait Islander people have higher levels of disability compared to the general population. Through interviews, I aim to collect the feelings, stories and thoughts about this directly from Aboriginal people with disability, or from their families and carers, or serviceproviders, where appropriate. I hope that what I find out by doing this research will help advocates and government funders to better understand this situation, so that appropriate ways of doing advocacy for Aboriginal people may be found.

Interviews will last from one to two hours and it may sometimes be necessary to do it twice if you have more to say or I need to check something with you.

All interviews will be done where you say you'd like to meet, provided I can get there with my wheelchair. Interviews will be done in private and will be audio taped. You will be able to stop the tape at any time, and ask that anything is removed from the tape. Nobody's name will be on the tape. Each tape will have a code number only. What is on the tapes will be typed up and these papers will also have numbers only. When the research has been finished, hopefully by July, 1998, the tapes will be wiped. Meanwhile the tapes will be kept in a safe location, where only the researcher can get to. No names will be used in the final report and any quotations of what anybody said will remain anonymous.

Whereas your confidentiality is protected you should note that this does not extend to issues of abuse and neglect, should the researcher come across any in the course of this study.

THIS IS TO CERTIFY THAT I, _____
hereby agree to participate as a volunteer in the above named project.

I hereby give permission to be interviewed and for these interviews to be tape
recorded. I understand that only the researcher will have access to the data obtained,
and that there will be no identifying evidence on any disks, cassettes and transcripts. I
also understand that the information may be published, but my name will not be
associated with the research.

I understand that I am free to not answer any questions. I also understand that I am
free to withdraw my consent and terminate my participation at any time, without
penalty.

I have been given the opportunity to ask whatever question I desire, and all such
questions have been answered to my satisfaction.

Signed:

Participant_____ Date_____/_____/_____

Witness_____ Date_____/_____/_____

Researcher_____ Date_____/_____/_____

Witness _____

Date / /

APPENDIX E.

Social Role Valorization theory of wounding

The wounds are:

1. Physical impairment,
2. Functional impairment,
3. Relegation to low ("deviant") social status,
4. Rejection, perhaps by family and neighbours, community, society and service workers,
5. Distantiation: Usually via segregation and also congregation,
6. Loss of natural, freely given relationships, and substitution of artificial 'boughten' ones,
7. Discontinuity with the physical environment and objects,
8. Social and relationship discontinuity,
9. Loss of control, perhaps even autonomy and freedom,
10. De-individualisation,
11. Involuntary material poverty,
12. Impoverishment of experience, especially that of the typical, valued world,
13. Exclusion from knowledge of and participation in higher order value systems that give meaning and direction, to life and provide community,
14. Having ones life wasted,
15. Jeopardy of being suspected of multiple deviancies,
16. Symbolic stigmatising, "marking", "deviancy-imaging", "branding",
17. Brutalisation, "death making",

18. Awareness of being an alien in the valued world; personal insecurity, perhaps dislike of oneself or rage,
19. Resentment, hatred of privileged citizens,
20. Awareness of being a source of anguish to those who love one.

(Wolfensberger, 1987, p.11)

APPENDIX F.

A table, showing some characteristics of participants as group data.

Characteristics of participants				
Gender:	M: 6 F: 3			
Age:	25 - 30: 1	30-35: 4	50 - 60: 3	60 - 65: 1
Disability:	spinal injury: 4			
	multiple disability: 2			
	intellectual disability: 2			
	brain damage: 1			
Health				
conditions:	diabetes: 2			
	asthma: 2			
	collapsed lungs: 1			
Education:	Some years primary			
	school only: 1			
	Primary school plus			
	some high school: 4			
	Special Education 2			
	Completed high school: 2			
Employed:	none			
Income:	all on Disability Support Pension			
Tribe:	Nyoongar: 5			
	Yamagee: 1			
	Strelley/Nyanga 1			
	Wongi 2			
From:	Wheat belt: 3			
	South West: 1			
	North West: 1			
	Kalgoorlie: 1			
	Midland: 1			
	Perth: 2			
