



**Australian Government**

**Australian Transport Safety Bureau**

**ATSB RESEARCH AND ANALYSIS REPORT**

Road Safety Research Grant – 2006

**Aboriginal People Travelling Well literature review:  
driver licensing issues, seat restraint non-compliance,  
Aboriginal health, Aboriginal disability**

Yvonne LM Helps  
Jerry Moller  
Research Centre for Injury Studies

**November 2007**





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# EXECUTIVE SUMMARY

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## Scope of the review

This review focuses on the interaction between access to safe and sufficient transport, and the effects on the wellbeing and health of Aboriginal people. Aspects under specific consideration are driver licensing, use of seat restraints, and health and disability needs. Attaining and retaining a drivers license for life, and travelling safely, which includes being trained to drive safely and being educated and aware of the efficacy of seat restraints are important issues for Aboriginal people. The health and disability conditions of Aboriginal people shape their transport needs, and lack of access to transport in turn influences disability and disability needs. The literature on these issues is not well developed. There are very few papers that deal with the interaction at any level of detail. There is however a number of papers that touch on aspects which are important. It was decided therefore to document what is known about South Australia, and what can be learnt from other Australian jurisdictions, with an emphasis on identifying the impacts of transport needs of Aboriginal society.

## Driver licensing

A driver license is often the entree into the workforce, an important part of the transition from school based education and learning, to vocational training and employment. It is a foremost form of photographic identification, and can assist in opening bank accounts, acquiring utilities (electricity, gas, telephone lines), and is an important security check for commercial air travel.

For people with ill health, disability or special health needs, a driver license may be the key to managing the best health possible. providing access where public transport may not be accessible.

The acquisition and retention of driver licenses is a crucial point in avoiding contact with the Criminal Justice System, in which (in South Australia) Aboriginal people are routinely over represented for unlicensed driving, suspensions and disqualifications, and other related offences that in isolation may be relatively trivial, but collectively can culminate in detention and exposure to the mental and health risks that that entails, particularly for Aboriginal people.

## Driver licensing needs

A drivers license is a gateway to many opportunities. Culturally appropriate and affordable driver education leading to a Learner license is essential. Qualified driver supervision is essential to accrue driving experience over a range of conditions in order to progress to a Provisional license. Registered, roadworthy and insured cars, as well as qualified supervising drivers are in short supply, with TAFE SA currently having only two staff and two vehicles available for practical supervision.

## Driver licensing responses

Regional TAFE SA and several metropolitan Aboriginal agencies and groups support Learner driver training and low cost access to testing. TAFE SA are currently engaged in securing funding to support the training and accreditation of additional Aboriginal Driver Education lecturers, purchase and insurance of driver training vehicles to assist with supervised driving hours. Vocational programs are able to offer limited driving tuition as a pathway from school to work –

increasing the amount of supervised hours, and broadening eligibility would assist more young people to successfully gain licenses.

## **Seat restraints**

The use of seat restraints provides the current best personal protection for passengers in motor vehicles that are involved in road accidents (air bags are rarely provided in every seating position).

For Aboriginal babies, infants and children, seat restraints are under utilised, and little information is available to communities about the efficacy, suitable type of restraint and correct fitting of the unit. Aboriginal people in general under utilise seat restraints, particularly in the rural and more remote areas and on homelands.

Road safety education and access to low cost restraint hire and qualified fitting are key elements of promoting driving for life, and reducing the risk of injury and death, growing health babies to healthy adults.

## **Seat restraint needs**

Consumer education relevant to Aboriginal communities on the importance of seat restraints and consequences for travelling unrestrained is a high need. Accessibility to car restraint systems at modest hire or purchase rates is particularly needed in the regional and remote areas. In combination with this, advice on correct restraint type for age and weight of travellers is essential, as well as provision of a fitting service to ensure correct installation of restraint systems.

## **Seat restraint responses**

The Australian Red Cross (SA) operates two safety stores in metropolitan areas of Adelaide, providing education and advice on travel safety, hire or purchase of seat restraint systems, and a fitting service. Discussions are underway to develop networks to deliver a similar service in a regional centre with local agency and community support, as a pilot to extend to other regional and remote areas. Coordination of this initiative by one institution would speed the process.

## **Health, transport and safety: a complex interactive system**

In South Australia there is an Aboriginal population of around 26,000 people. Half of these live in urban areas, while the remaining half is split evenly between rural and remote areas.

Aboriginal people have poor health and great needs for better health preventative care and treatment. Overall Aboriginal health compares poorly with non Aboriginal health and with the health of other indigenous peoples living in developed nations. Lack of access to services is a contributor to poor health and lack of health creates a need to travel to receive high level health treatment services.

The need for health services generates a need to travel. Appropriate care is often a great distance from where Aboriginal people live. This results in delay in using health services so that travel is undertaken when the need is acute. This can be in an emergency or when the patient is very sick. Even if the patient is transported by ambulance or aircraft, family members are left to travel using their own means. Such trips occur in poorly prepared and maintained vehicles a time of great stress. At these times, even if public transport is available, it does not provide the privacy needed.

There is therefore a complex interaction between health needs and transport, Aboriginal cultural needs and the safety of the trips generated.

## Health needs

Lack of adequate transport systems interact with the health and cultural needs of Aboriginal people to produce a situation where a twofold problem occurs. Firstly Aboriginal people often travel unsafely at times of stress and health crisis in the family. Secondly, reluctance to travel induced by lack of access to safe travel contributes to under-servicing of health needs and the continuation poor health among Aboriginal populations:

- Transport for Aboriginal people needs to acknowledge and respond to the cultural needs to travel and the importance of family and community support systems. There is a need for increased access to safe transport in all areas but especially in rural and remote areas where greater health needs coincide with poor road systems, lack of publicly funded transport and increased travel distances,
- The nature of health needs and the distribution of health treatment resources generate a need for travel. While there are patient transport subsidies available, they are not able to allow agencies to adequately respond to the needs of Aboriginal people and their families,
- The need to travel by Aboriginal people can be at least partially offset by redistributing health services. These services are highly fragmented with separation of planning for primary medical care, primary health care, specialist consultation and community support services. This result in duplication of travel and higher than necessary transport costs while wasting the resources that are available,
- Transport for Aboriginal people and the goods and services they need has the potential to build connectedness between Aboriginal people and between Aboriginal people and the general community,
- Addressing the lack of transport in rural and remote areas will not be easy but it should be remembered that in South Australia this means addressing the need of 13,000 people,
- In the urban areas, racism on public transport and taxi services needs to be addressed,
- There is also a need to recognise that public transport services may not adequately meet the needs of patient and families in times of crisis and that more supportive and private means are required, and
- Aboriginal society has a different age distribution to non-Aboriginal society in South Australia. Unless care is taken, modifications to health service to meet the needs of the majority population could increase rather than decrease transport problems associated with health care for Aboriginal people.

## Responses

The issues identified in this paper need a cooperative multi-sector response and a level of cultural sensitivity not shown so far. Action is required at a number of levels

- Core policy development that builds the communication strategies necessary for inter-sectoral cooperation,
- The transport needs of localities with high health needs should be assessed and a coordinated response put in place. This response might include:

- improvement of road systems,
  - use of shared community transport with accredited drivers in safe, well maintained vehicles to support patients and their families as they access health care and undertake cultural responsibilities such as attending funerals,
  - Coordination of agency personnel’s use of transport and freeing up of restriction on non employee travel in agency vehicles,
  - Increasing driver training, and
  - Motor vehicle maintenance schemes and safety checks.
- Advocacy by Aboriginal agencies to ensure that needs are properly understood and that the policy options for the general population will meet the needs of the younger and more highly stressed Aboriginal population, and
  - Acceptance by government that in order to improve Aboriginal well being that the resources committed should be in line with the high level of need generated by poor health, cultural disruption and geographic distribution of health service.

## **Disability, transport and safety**

There is a dearth of systematic literature on Aboriginal disability. Aboriginal disability policy and services operate in the shadow of mainstream services and ideas in a system which diversifies responses across a wide range of departments and agencies.

Aboriginal concepts of disability appear to be poorly understood by policy makers and service providers. There has been little research published on Aboriginal disability possibly due to the small numbers of Aboriginal people involved with medical disability, limiting the study of this issue. However, while number are small in relative terms the prevalence is much greater and more complex than in non Aboriginal society. There is a great need to study Aboriginal disability in a systematic and culturally sensitive manner in order to determine what services are needed.

The lack of good information about Aboriginal disability in general has an impact on the understanding of transport issues for Aboriginal people with a disability and their families. We could find no literature that systematically studies Aboriginal disability needs and issues of access and transport. Issues of access to services are raised for all disabled people and it is clear that the population distribution and economic and social well being of Aboriginal people generates specific critical needs.

### **Disability needs**

The lack of information should not however be used to delay action. The number of Aboriginal people with a disability is clearly underestimated due to lack of culturally appropriate systems to identify need. It is clear that there are more than a thousand Aboriginal people with impairment or disability as defined by a health based definition and at least 10,000 who can be identified as being affected by broader social and educational disabilities.

While transport systems are only one barrier to access to services for assessment and support, they can be the focus of attention as other barriers are being addressed.

A person with a disability requires proper assessment and support. This can only be done if the services are easily accessible. Where a disability exists there are significant pressure on families and caregivers in meeting the direct load generated by the disability. There are multiple assessment

meetings with a range of professions, meeting the different needs for daily living and adjusting to different education and support system.

It is important that services are delivered in a manner that does not increase the costs to families by requiring a great deal of travel. Disability needs are less common than general health needs, so safe transport systems will either need to piggyback on the health system arrangements or will need to be especially arranged for individuals and their families.

## **Responses**

It is likely that the improvement of transport access for all Aboriginal people will be needed to provide a foundation for improved access to disability services. The recommendation made for improvements to deal with health issues therefore apply to disability.

In addition, it is clear that transport that is appropriate to the needs of each disabled Aboriginal person is required. Transport needs of the person and their family needs to be a core part of assessment. It cannot be assumed that the generic response of policy makers and services to disabilities is adequate for Aboriginal people. Neither should it be assumed that passing responsibility to general Aboriginal agencies that have no specific expertise in disability will result in the necessary changes. There is a need to specifically address the transport needs of Aboriginal people with disabilities at core policy, departmental and local level. Failure to do so will mean that Aboriginal people do not receive the assessments or service they need and that they will be placed at risk trying to offset these deficits in ways that risk the safety of Aboriginal families and communities.

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## ABBREVIATIONS

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ABS	Australian Bureau of Statistics
ACE	Adult Community Education project
ACCHS	Aboriginal Community Controlled Health Services
ACS	Automated Coding System
ADAC	Aboriginal Drug and Alcohol Council (South Australia)
AHCSA	Aboriginal Health Council of South Australia
ANZDATA	Australia and New Zealand Dialysis and Transplant Registry
AIHW	Australian Institute of Health and Welfare
APOSS	Aboriginal Prisoners and Offenders Support Service
APTW	Aboriginal People Travelling Well
APY Lands	Anangu Pitjantjatjara Yankunytjatjara Lands
ATSB	Australian Transport Safety Bureau
CBD	Central Business District
CDEP	Community Development Employment Program
CHD	Coronary Heart Disease
CKD	Chronic Kidney Disease
CRCAH	Cooperative Research Centre for Aboriginal Health
CSOs	Community Service Orders
CSTDA	Commonwealth State Territory Disability Agreement
CVD	Cardio Vascular Disease
DDA	Disability Discrimination Act
DECS	Department of Education and Children's Services
DoTARS	Department of Transport and Regional Services
ESD	English as a Second Dialect
ESL	English as a Second Language
ESRD	End Stage Renal Disease
GP	General Practitioner
HACC	Home and Community Care
ICD-10	International Classification of Diseases
NPY	Ngaanyatjarra Pitjantjatjara Yankunytjatjara Womens Council



RAA	Royal Automobile Association
SAAHP	South Australian Aboriginal Health Partnership
SAPOL	South Australia Police
TAFE	Technical and Further Education
THC	Delta-9-Tetrahydrocannabinol, the psychoactive ingredient in cannabis
UICRG	Flinders University-Industry Collaborative Research Scheme
VORT	Vehicle on Road Testing
WHO	World Health Organization



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# 1 INTRODUCTION

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Negative impacts on health are not restricted to physical injury or death due to involvement in traffic accidents, but encompass a range of issues that may not immediately appear to be directly related to transport accessibility.

## ***Road transport related injury and death***

Road traffic accidents are significant causes of injury requiring hospitalisation, and of injury resulting in mortality in Australia. The Australian Bureau of Statistics (ABS) collects and maintains a routine mortality data registration system, coded to the current International Classification of Diseases (ICD-10) (WHO 1992). Information from this national dataset can provide demographic information about the deceased, principal diagnosis of death, multiple (underlying) causes of death, and in the case of injury related deaths, the major external cause of death (for example, road traffic, suicide, homicide, fall, drowning). Injury related, or external cause deaths are distinct in the ABS collection in that they are manually coded, in contrast to other deaths, which are coded with Automated Coding Software (ACS).

National hospital separations data are collected and maintained over time by the Australian Institute of Health and Welfare (AIHW), in its National Hospital Morbidity Database (NHMD). Case data are coded to the current edition of the ICD-10-AM (Australian Modification) (National Centre for Classification in Health 2002). Although a substantial source for information on admitted injury cases, it should be noted that only a proportion of non-fatal yet serious injury result in a hospital stay, with many cases being attended to in Emergency Departments, or same day hospital treatment (Driscoll, Harrison et al. 2004) or by doctors in General Practice.

While road safety promotion and strategies appear to have resulted in lower, and decreasing rates of hospitalised injury over time for non-Indigenous Australians in Western Australia, injury hospitalisation rates for Aboriginal people in that jurisdiction are higher, and rising over time (Cercarelli, R and Knuiman 2002).

## ***Transport issues as contributing factors to health and wellbeing***

The ability to control dust nuisance that can exacerbate eye conditions, skin disorders and respiratory infections can be improved by sealing community streets and the roads that lead in and out (Bailie, Siciliano et al. 2002). Sealed roads can also improve the delivery of fresh foods and other consumables over a longer period of the year, where unsealed roads may be unpassable at some times.

Many Aboriginal people experience transport problems such as unavailability of public transport in remote areas (ABS 2004). This is significant, as Aboriginal Australians are less urbanised and tend to dwell in more remote regions than other Australians (ABS 2002).

The ability to participate in employment, social engagements, cultural events and responsibilities and day to day business of life is possible, whether in urban, rural or remote settings, is often influenced by access to suitable transport.

## ***Aboriginal culture***

Aboriginal culture is rich and varied. In more traditional areas the ancient culture is lived every day and is the source of health. In other places especially where there is a mix of Aboriginal peoples

from a variety of places and a strong influence of white culture there are many different cultures and often different views about culture in one community.

“Since 2002, WDNWPT emphasised that this cumulative experience was best described through a migrant prism of ‘dislocation’ rather than muffled ‘relocation’. It is a schism, an abrupt and profound separation from all that was familiar and sustaining, all that went before. Yanangu describe how ‘dislocation’ strikes at the very core of their identity, disrupting linked values of family and relatedness (walytja), country (ngurra) and Dreaming (tjukurrpa), the basis of Yanangu well-being. The enforced disconnection of individuals and family is central.” (Rivalland 2006) Pg 13

It is also not well recognised in the wider Australian community that there are many Aboriginal groups, some with similar customs and practices, some with differing or unique beliefs and habits. Responsibilities, knowledge, protocols and correct behaviour are complex issues:

“Yanangu consistently describe the entangled, debilitating sadness, insecurity and loneliness brought on by being so far from country and family. It is culturally inappropriate and unwise to always remain in one place, especially in another Aboriginal person’s country where social, spiritual and nutritional activities are lacking, e.g. hunting. With the frustration and emptiness of boredom, reduced networks and lost opportunities, individuals can wait endlessly for visits or even a familiar face (Rivalland 2006) Pg 13

Nevertheless, Aboriginal commitment to social and family responsibility, reciprocal gift giving, the importance of place and heritage is a fundamental foundation that influences health and the need to travel.

The literature on culture and health is wide ranging. The health review has chosen to start with more traditional living peoples as this ancient culture underpins what it means to be Aboriginal in all settings to a greater or lesser extent.

### **Car culture**

Attitudes and beliefs around car usage and what the car represents within the community can exert strong influence on behaviours, which may at times result in risk taking that would otherwise seem unwise.

Difficulty in obtaining a driver’s license can prompt inappropriate behaviour, including driving unlicensed, driving under-aged, and involvement in road traffic accidents due to lack of experience. Barriers may include language differences, reading and writing difficulties, distrust of police officers (in some areas licensing is overseen by local police), and apprehension about dealing with agencies (government licensing authorities). Conditions of poverty restrict access to safe private vehicles, often leading to use of lower standard cars and overcrowding (Watson, M, Elliott et al. 1997).

Kinship obligations may also influence an Aboriginal person’s decision to drive unlicensed. It might be argued that being in possession of a vehicle places an Aboriginal person within the same obligation as food sharing is in the kinship system:

"Aboriginal people have a system unlike non-Aboriginal people, which arises from kin, friends and the family structure."

"Traditionally in Aboriginal culture, it was the custom that when the hunters returned from their kill, the food was shared among the tribe. This system helped Aboriginal people survive, and down through the years the same system still operates." Aunty Veronica Brodie, quoted in ‘An Aboriginal Perspective’ in (South Australian Department of Community Welfare 1989)

Pressures to drive come from a variety of sources, in some cases from people to whom it is culturally inappropriate to refuse, and for attendance at events which it is culturally important to attend. Time restrictions may also influence people to drive whether licensed or not.

For urban dwelling Aboriginal people, emotional distress and depression may result from being unable to travel at particular times to traditional country, and lack of means of travel may influence people to undertake unsafe or illegal means in order to fulfil cultural obligations (unlicensed drivers, unregistered and unsafe vehicles).

Attitudes and beliefs around car usage and what the car represents within the community can exert strong influence on behaviours, which may at times result in risk taking that would otherwise seem unwise.

Conditions of poverty restrict access to safe private vehicles, often leading to use of lower standard cars and overcrowding (Watson, M, Elliott et al. 1997). In Western Australia, an interview study conducted in remote Aboriginal communities reported that lifestyle and culture may result in different responses to road safety education, and that use of seat restraints by adults was most times or all the time (Cercarelli, RL, Ryan et al. 2000). However, the same report found that adults observed that many children never wore restraints, and some children only wore them sometimes (Cercarelli, RL, Ryan et al. 2000).

Parent's attitudes to care of their children also differs; an Aboriginal parent is more likely to release a child from seat restraints to comfort them, and proceed to travel with them on their lap because *they* are providing the safety for their child (Wanganeen Irene 2005).

## **1.1 Purpose of this review**

This literature review aims to identify issues around driver licensing, seat restraint non-compliance, conditions of health and disability, and underlying road safety for Aboriginal people in South Australia. We draw together literature to describe what is known, and to describe existing strategies or solutions that may be operating in settings outside the state. Communities in urban, rural and remote areas are affected in different ways, and the effect of this on individuals and communities is not well understood in the wider population. This paper reviews available literature on barriers to driver licensing (and therefore, safe travel) for Aboriginal people, and explores some of the consequences of inability to travel safely, appropriately and in a timely manner. The disability of Aboriginal people shapes their transport needs and lack of access to transport in turn influences disability and disability needs. The literature on these issues is not well developed. There are very few papers that deal with the interaction at any level of detail. There is however a number of papers that touches on aspects which are important. Existing reviews on the subject of Aboriginal road safety are considered, and gaps and shortfalls in the available literature are discussed. Material specific to South Australia is reviewed, as well as similar subject information available for other jurisdictions. This review is a component of a community participatory research project funded by the ATSB.

## **1.2 Justification for this review**

Unsuitable, unroadworthy vehicles and issues such as seatbelt non-compliance, unlicensed driving, speeding, maleness and alcohol involvement may be significant factors influencing road safety, particularly in the more remote areas (Watson, M, Elliott et al. 1997; Treacy, Jones et al. 2002). The severity of road accident outcomes increases when older cars are involved, and defects relating to the age and condition of the vehicle are also contributing causes in crashes (Paine 2000). Response time to casualties of motor vehicle accidents in the more remote areas impacts directly on the health

outcome for the patient, and retrieval by road or even by air via the Royal Flying Doctor Service (RFDS) can extend the management of trauma treatment from the 'Golden Hour' to the 'Golden Day', or longer (Croser JL 2003). In 2000, a critical review and research report came to the conclusion that literature pertaining to Indigenous injury from road trauma was underdeveloped, and that there was little available material from a social health perspective (Brice 2000). Lack of research has previously been pointed out in other reports seeking to describe Indigenous road trauma, as well as shortcomings in data collection and identification of victim (Moller 1996; Watson, M, Elliott et al. 1997; R & M Consultants 1999). Indigenous populations have also been identified as being at greater risk of mortality and hospitalisation than the rest of the population, particularly in rural and remote areas, and therefore in need of further investigation and intervention (Edmonston, Dwyer et al. 2002; Macaulay, Thomas et al. 2003).

In South Australia there is an Aboriginal population of around 26,000. Half of these live in urban areas, while the remaining half is split evenly between rural and remote areas.

Aboriginal people have poor health and great needs for better health preventative care and treatment. Overall Aboriginal health compares poorly with non Aboriginal health and with the health of other indigenous peoples living in developed nations. Lack of access to services is a contributor to poor health and lack of health creates a need to travel to receive high level health treatment services.

The need for health services generates a need to travel. Appropriate care is often a great distance from where Aboriginal people live. This results in delay in using health services so that travel is undertaken when the need is acute. This can be in an emergency or when the patient is very sick. Even if the patient is transported by ambulance or aircraft, family members are left to travel using their own means. Such trips occur in poorly prepared and maintained vehicles a time of great stress. At these times, even if public transport is available, it does not provide the privacy needed.

There is therefore a complex interaction between health needs and transport, Aboriginal cultural needs and the safety of the trips generated.

There are many published reports and some grey literature that offer valuable and detailed insight into aspects such as road safety, injury and death statistics, and transport accessibility issues that impinge on the wellbeing of Aboriginal communities. It is important to consider more fully the range of underlying factors that result in negative outcomes for health and wellbeing, that may relate to the availability of safe and sufficient transport, and to explore effects beyond those that are measurable in terms of injury hospitalisations and deaths, or incarceration rates related to motor vehicle offences. It is much more difficult to directly measure the effect on individuals who suffer from interpersonal violence because they cannot physically transport themselves out of their situation, or the effect on children for whom access to regular schooling is affected by distance, or the ability of families to prosper when fresh food choices are severely restricted due to lack of heavy transport access to their area for delivery of consumables. Lack of integrated and up-to-date evidence hinders progress in the provision of equitable access to safe transport for Aboriginal people in many settings and geographical situations.

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## 2 METHOD

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### 2.1 Search strategy

To investigate issues underlying inability to travel well, we have networked to identify and link a wide group of people from agencies, organisations and groups with an obligation for, or interest in, Aboriginal health and welfare. Infrequent meetings (twelve from March 2005 to December 2006) in a forum style have been held, at which, particularly in the early stages, common themes across the range of agencies represented were obvious (more fully described in (Helps YLM, Moller J et al. 2007)). Specific interest meetings have also been held on topics such as Indigenous driver licensing issues, road safety education in the Aboriginal context, and a joint meeting with the South Australian Indigenous Road Safety Taskforce was convened. Eleven adverse impacts on Aboriginal wellbeing have been identified so far, ten of which were strongly related to issues of accessibility to safe, reliable, timely transport. The eleventh theme was related strongly to incarceration and acquired drug dependencies, with a peripheral focus on transportation needs on release from detention. This is a serious issue, but considered outside the scope of the present road safety project, and may be approached at another time when an appropriate method has been established. In this literature review, two themes are addressed; issues of driver licensing affecting the ability to travel well, and vehicle travel safety for infants and children.

A preliminary analysis of formal and informal literature showed that there were few, if any, articles that systematically dealt with transport needs related to disability and health issues among Aboriginal people. It was decided therefore to document what is known about Aboriginal health, disability and disability services in South Australia with an emphasis on identifying the impacts of transport needs of Aboriginal society.

#### 2.1.1 Range and focus

The breadth of literature considered in this review has encompassed mortality and hospitalisation statistics, Criminal Justice data, literature reviews, government agency reports, electronic sources from the World Wide Web, and quite a substantial amount of personal communication, which was invaluable in understanding facets of what travelling well means for Aboriginal people. Literature specific to South Australia from 1997 to the present has been considered, and sources from other Australian jurisdictions from 1996 to the present. The focus has not been singular, it has been a multi-faceted exploration, reflecting the complexity of both the Aboriginal notion of travelling well, and the difficulties in doing so. In recognition of this it should be acknowledged that this review itself is incomplete – it addresses only four of the themes identified in the forum series (referred to in main report). As such, it can only partially inform, and it is our intention to expand the review as time goes on to cover the other existing themes, and more as they arise. Around 40 or so sources have been referenced, although many more have been considered to arrive at this compilation.

A preliminary analysis of formal and informal literature showed that there were few, if any, articles that systematically dealt with transport needs related to health, disability, licensing and seat restraint use. A plethora of material is available that describes transport as a key factor in maintaining the health of Aboriginal people, but this literature describes a basic need without systematically analysing how the need is generated. The informal literature written for clients of health services describes the transport initiatives of each health service, once again reflecting its importance. Our focus on health presents us with some interesting issues of definition. The Aboriginal view of health focuses on social and emotional well being as well as illnesses and diseases. Western medical literature is divided into two parts, that which deal with wellness and prevention and the other much

larger literature that focuses on specific diseases and their cures. This review covers a range of ideas drawing each approach to understand the way in which ideas about health influence ideas about transport. A model that considers the Aboriginal population and its geography, patterns of disability and health issues, and the responses of policies and services was used as a basic framework for analysis.

### 2.1.2 Websites

The Department of Transport and Regional Services (DoTARS) is a Federal government agency involved in the provision of transport networks, regional development to ensure better access to opportunities and services for communities, in provision of natural disaster relief and recovery plans, and provides policy advice to the Ministers of Transport and Regional Services portfolio. In its capacity, it supports research on travel safety

<http://www.dotars.gov.au/roads/publications/index.aspx> (Department of Transport and Regional Services 2004)

The Australian Transport Safety Bureau (ATSB) is an operationally independent body within the Australian Government Department of Transport and Regional Services (<http://www.atsb.gov.au/road/pubs.cfm>). This site had research reports on national road safety, state or territory breakdowns, and research specific to Indigenous Australians.

The Aboriginal Drug and Alcohol Council (SA) website provided a key report based on earlier community research (Watson, M, Elliott et al. 1997) <http://www.adac.org.au/>

The Aboriginal Health Council of South Australia (AHCSA) is the peak body representing Aboriginal community controlled health and substance misuse services in South Australia at a state and national level. AHCSA commissioned a key report in partnership with Transport SA in 2000 (Brice 2000). The website provided information on research and ethics, publications and resources. <http://www.ahcsa.org.au/content/1>

The Australian Bureau of Statistics (ABS) compiles statistics across a broad range of areas including deaths data, demographic information, crime and justice data, and also produce joint reports with specialist agencies in health, welfare, economics, justice and other areas. <http://www.abs.gov.au/>

The Australian Institute of Health and Welfare has publications on a range of Indigenous health and welfare topics. <http://www.aihw.gov.au/index.cfm>

The Research Centre for Injury Studies (incorporating the National Injury Surveillance Unit) has publications on hospitalisations and deaths due to injuries (including road related injury), with some publications specific to Aboriginal and Torres Strait Islander people. <http://www.nisu.flinders.edu.au/>

The Australian Indigenous Health *InfoNet* provides information on many areas of Indigenous health, has a comprehensive bibliographic database of literature on Australian Indigenous health, and has several 'yarning places' (electronic networks) that encourage information-sharing and collaboration, one of which is devoted to Indigenous road safety. <http://www.healthinonet.ecu.edu.au/>

A NSW website that was developed to assist Aboriginal people in overcoming problems related to driving and driver licensing <http://www.drivingproject.org/index.htm> (NSW Road Traffic Authority, NSW Attorney General's Department et al.).



### **2.1.3 Internet search engines searched**

The academic literature was searched using Ingenta, Medline and Google scholar. A wider search of the entries accessible via Google was also made and a specific search of the South Australian government domains. A variety of terms were used including combinations of Aboriginal, transport, disability, indigenous, access, injury, unlicensed, driver, child restraints, booster seats, seat belts. A model that considers the Aboriginal population and its geography, patterns of disability and the responses of policies and services was used as a basic framework for analysis.

### **2.1.4 People interviewed**

Many informed and wonderful people contributed to this review in the form of interviews, personal telephone and email communications. The contribution of the following people is gratefully acknowledged:

- Dr Trevor Bailey
- Ms Deb Frank
- Mr Pierre Gebert
- Ms Sherree Goldsworthy
- Ms Tania King
- Mr Tony Lindsay
- Detective Inspector Trevor Lovegrove
- Ms Maree McColm
- Mr Jerry Moller
- Mr Lindsay Nash
- Mr Bob Ramsay
- Senior Sergeant Graham Schaedel
- Mr George Shearer
- Associate Professor Malcolm Vick
- Ms Irene Wanganen,
- Mr Klynton Wanganen
- Ms Judith Welgraven
- Ms Bonnie Wizer

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## **3 DRIVER LICENSING ISSUES**

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### **3.1 Pressures and barriers**

Pressures to drive come from a variety of sources, in some cases from people to whom it is culturally inappropriate to refuse, and for attendance at events which it is culturally important to attend. Kinship obligations and time restrictions may also influence an Aboriginal person's decision to drive unlicensed.

Barriers may include language differences, reading and writing difficulties, distrust of police officers (in areas where licensing is overseen by local police), cost of testing and licenses, and apprehension about dealing with agencies (government licensing authorities). Affordable, appropriate and accessible licensing and driver training have also been identified as barriers to access to safe transport in rural and urban areas of New South Wales (Mid North Coast Aboriginal Health Partnership 2001; Western Sydney Area Health Service 2003; Western Sydney Area Health Service Centre for Public Health 2003).

Place of residence also has an effect on travel. Many Aboriginal people experience transport problems such as unavailability of public transport in remote areas (ABS 2004). This is significant, as Aboriginal Australians are less urbanised and tend to dwell in more remote regions than other Australians (ABS 2002). Difficulties with written language and comprehension are known barriers to vehicle licensing, and low income status makes multiple test attempts (which attract a fee) impractical. Low accessibility to culturally appropriate driver education and training for Aboriginal communities in rural to remote areas in South Australia has previously been identified through community consultation (Watson, M, Elliott et al. 1997).

#### **3.1.1 Personal identification**

Personal identification is a requirement for driver licensing. At least three forms of evidence of identity are required in South Australia, and criteria apply (Department of Transport Energy and Infrastructure 2007). A number of documents listed in Category A are accepted in order to establish 'Evidence of Existence and linkage between Identity and the Applicant'. Category B documents are aimed at establishing 'Evidence of Use of the Identity'. A further selection of documents are listed that can establish 'Evidence of Residential Address'. In many cases, due to living circumstances, lack of accounts with financial institutions or service providers, or perhaps even not having been registered at birth, Aboriginal people (in particular those living remotely), find it difficult or impossible to compile the necessary documentation. Lack of a driver's license or other photographic identification also prohibits persons from travelling on commercial airlines.

### **3.2 The driver licensing process in South Australia**

In South Australia (as at January 2007) the cost of a hard copy Driver's Handbook (see 3.1.5 for free electronic access), which must be studied to attempt the Learner's written test was \$5, the cost of the Written Road Rules test \$25, the cost of the Learner's permit \$40 plus a \$15 administration fee for issue of license. 'The Driving Companion', which incorporates the compulsory 50 hour driving experience 'Log Book' costs a further \$5. In total, it costs \$90 if successful on the first attempt at the Learner's permit (if using the log book system). Estimated proportion of people who pass the test on the first attempt ranges from 50-55%, and varies across areas and regions of the state (Gebert 2007). No figure is available specifically for Aboriginal first pass percentages.

Frustration in not meeting the criteria for a driver's license, or being ineligible due to existing criminal offences can prompt inappropriate behaviour and adverse outcomes, including driving unlicensed (Charles Darwin University 2000), driving under-aged, not using seatbelt restraints and involvement in road traffic accidents due to lack of experience. Data collected in the Northern Territory from 1996-99 showed that the proportion of fatalities in accidents where the vehicle driver was unlicensed was nearly 50% for Indigenous people, but less than 10% for non-Indigenous people (ATSB 2004).

### **3.2.1 Programs**

#### **Northern Territory**

Remote communities have had the opportunity for the past seven years of participating in the Remote Areas Driver Instructor Program. Hosted by Charles Darwin University, this program operates from Central Australia to Arnhem Land, training instructors (now numbering 150) in communities. By January of 2004, the program had been successful in the licensing of over 900 drivers (Charles Darwin University 2000). In the same year, a driver safety video was scheduled for distribution, showcasing local students. The Community Based Instructor courses develop individuals to a standard that gains them a Certificate IV in Driving Instruction, accrediting them with a Restricted Driving Instructors Endorsement. Development of individuals contributes to the capacity of the community, building empowerment and ability to be self determining. The program is committed to long term goals and strategies to enable remote living people to overcome driver licensing difficulties, rather than once-off solutions.

#### **Queensland**

The Queensland Aboriginal peoples' and Torres Strait Islander peoples' Driver Licensing program seeks to increase the rate of license holding among Indigenous drivers, a major contributor to high incarceration and road trauma rates among Indigenous peoples. The program is led by Queensland Transport in partnership with Police, Communities, Emergency Services, Justice and Attorney General, Education, Training and the Arts, Department of Corrective Services and Queensland University of Technology and James Cook University. It has secure Queensland government funding for the period 2006-2011. It centres around the delivery of learner and provisional license testing and issuance into remote communities by a dedicated licensing team based in Cairns and is supported by developing educational initiatives to prepare community members to successfully sit their license test.

#### **New South Wales**

Cultural barriers to driver licensing have been recognised in NSW, resulting in the Adult Community Education (ACE) North Coast Driver Education Project, funded by the Road Traffic Authority, the Attorney General's Department, and the Motor Accident Authority in that state (<http://www.drivingproject.org/index.htm>). The driver education program was developed by Lismore Adult Community Education (ACE), and is called On the Road. The program aims to reduce the numbers of Aboriginal people from the Far North Coast area appearing in the criminal justice system through assistance and education in achieving or regaining a driver license, driver training, use of a computerised road knowledge test, and negotiating fine payment.

#### **South Australia**

In Adelaide, Kura Yerlo (Kaurana words, meaning 'by the sea') Incorporated is an Aboriginal Community Centre in the western suburbs that conducts a Learner's Education Course (in collaboration with Tauondi College), providing instruction for Aboriginal people to prepare them to complete the Learner's permit test. This is conducted in groups of 10-26, in sessions lasting two

hours, over a period of four weeks. It costs \$10 to enrol in the course (which covers afternoon tea for participants over the four weeks of sessions), and participants are required to purchase their own copy of the Driver's Handbook (\$5). As the educator is a trained Driving Instructor, funded through Taoundi College, the service is offered to the community free of charge, for participants who are able to show a Certificate of Aboriginality (some non-Aboriginal and migrant people find this mode of learning better suited to them, and they pay for the course).

The driving instructor works through the Driver's Handbook, assisting the group with literacy and comprehension difficulties, and encouraging individuals to work with each other to understand the content. Computers are available for attempting a computerised test of the material that is based on the Learner's Manual, available on the Royal Automobile Association (RAA) website (<http://www.raa.net/page.asp?TerID=192&rnd=0.7577293>). Computer access is free of charge and funded from Community Benefit SA for the 'Hard Drive to Stay Alive' project to support driver education.

At the conclusion of the course, an accredited Learner driver permit tester, employed by Technical and Further Education, South Australia (TAFESA), conducts testing in-house. The student is required to cover the cost of the learner permit testing. This reduces the barrier of low income status, particularly as some individuals may not attain the permit in the first instance, and will repeat the instruction before resitting the test. It is also less intimidating to be tested in familiar and non-threatening surroundings at Kura Yerlo than it would be for some at the government registration office. Once the Learner permit is achieved, Kura Yerlo staff refer participants to the Community Development Employment Program (CDEP) for progression to the Probationary license (a fee pay service).

In regional areas of SA, driving hours supervised by TAFE instructors can be negotiated with the client, using the TAFE driver education vehicle. While the requirement for progressing to a Provisional license is 50 supervised driving hours, more hours may be invested by the TAFE instructor to ensure that the standard of practical ability is sufficient to equip the client for independent driving.

The process described above is replicated in other areas around the state by two TAFE employed Driver Education Instructors. In the Yorke Peninsula town of Moonta, the classes are held at an Aboriginal community centre in the main street, called Yanggalagawi (Narrunga for 'meeting place'). The other instructor covers a vast area from Port Augusta to Coober Pad and across to Ceduna and the upper Flinders Ranges.

In the northern Adelaide suburb of Elizabeth Vale, Muna Paiendi Aboriginal Health Service hosts these TAFE classes as part of its service to clients. Muna Paiendi is Kaurna for 'first seek knowledge/information'.

Marra Dreaming is an Aboriginal Community Centre in the north of Adelaide (Salisbury) that specialises in encouraging and promoting art and craft. The centre has also implemented the TAFE Driver Education Course.

A similar program is run in 'The Nunga Room' at the Adelaide City Campus of TAFE, where the Driver Education Course is free for people who are registered with Aboriginal Employment Programs.

TAFESA also supported a Driver Education program that is hosted by the Adelaide Community Development Employment Program (CDEP) at Cavan, also in the outer northern area of Adelaide.

Accessibility of this driver education program would be increased dramatically if there was capacity to employ more suitable and qualified Driver Education Instructors. The current two Instructors are

thinly stretched, and under considerable strain to maintain the quality of their service over the size of the state, and the range of communities that wish to access the service.

### **3.2.2 Accessibility of programs and licensing costs**

Inability to access or afford licensing and driver training have been also been identified as barriers to access to safe transport in rural and urban areas (Mid North Coast Aboriginal Health Partnership 2001; Western Sydney Area Health Service 2003). Difficulties with written language and comprehension are known barriers to vehicle licensing, and low income status makes multiple test attempts (which attract a fee) impractical. Low accessibility to culturally appropriate driver education and training for Aboriginal communities in rural to remote areas in South Australia has previously been identified through community consultation (Watson, M, Elliott et al. 1997). Cultural barriers to driver licensing have also been recognised in NSW, resulting in the Adult Community Education (ACE) North Coast Driver Education Project, funded by the Road Traffic Authority, the Attorney General's Department, and the Motor Accident Authority in that state (<http://www.drivingproject.org/index.htm>).

Other barriers include financial cost as well as physical access to licensing programs. Even where there is no out of pocket training expense to the client, going through the licensing system can be financially prohibitive.

### **3.2.3 Supervised driving hours**

The ability of any learner driver to advance to a Probationary (P) license is dependent on accumulating 50 hours of supervised driving under a range of conditions. The first hurdle is to identify a willing and suitably qualified driver to supervise the Learner. This is ideally met through the use of a paid Motor Driving Instructor, but for most Learners, the cost is prohibitive. It is more common that a family member or friend will provide the bulk of supervision and practice, and a portion will occur with a paid instructor toward the time when the Learner intends to undergo the test to obtain a P license. The South Australian requirements for supervision are:

“A Qualified Supervising Driver must:

- have an unconditional license authorising the person to drive a Class C vehicle (or an equivalent foreign license as approved by the Registrar of Motor Vehicles),
- have held an unconditional/full license for the last 2 years without disqualification,
- not hold a provisional or probationary license or be subject to the condition of “good behaviour”, and
- not have a blood alcohol reading of more than 0.05 or the presence of THC (Cannabis) or Methylamphetamine (Speed) in their blood or oral fluid.” (Department of Transport Energy and Infrastructure 2006)

The second hurdle is to find a vehicle that is roadworthy and registered. This will often belong to the Supervising Driver, who may not have insurance cover for a younger and inexperienced driver. There are also the issues of time pressures on the volunteer Supervisor, as well as the cost of fuel involved, which can be considerable if bought in remote locations. Where a professional Instructor is used, these issues are already addressed, but once again, cost limits the amount of hours possible.

As described in the South Australian example in Section 3.1.3, TAFE driving instructors have a limited capacity to provide supervised hours in the insured TAFE Driver Education vehicle. However, there are many instances where young Learners cannot access family to assist in this process, and the demand and circumstances are beyond the capacity of the current TAFE resources.

### 3.3 Criminal justice system issues

Criminal Justice data is a source of information that is increasingly being utilised in conjunction with other data sources to explore factors underlying negative health outcomes. In particular, this has been relevant to deaths in custody (McDonald 1996), violence and sexual violence (Allan and Dawson 2004) and has also been used to examine unlicensed driving behaviour (Watson, B. 2004).

Criminal justice system data in South Australia have shown that apprehensions and convictions recorded for Aboriginal people are particularly high for road traffic related offences. In the 2002-03 financial year, 35.3% of total Community Service Orders (CSOs) imposed on Aboriginal people were for traffic infringements. In the same time period, 22.8% of offences resulting in imprisonment were traffic related (Moller J Director New Directions in Health and Safety 2005). Repercussions of being served a CSO, and of failing to serve it out are numerous. This trend is not unique to South Australia, with data reported from New South Wales showing that offences related to driving licenses were ranked third (after assault, and disorderly conduct) in total convictions recorded for Aboriginal people in 2001 (NSW Attorney General's Department 2003). A national survey of a sample of Aboriginal people in 2002 further indicates links between difficulties in travelling to the places needed, remoteness of area of residence, and arrests and incarcerations (ABS 2004). This often results in financial hardship, in mental and spiritual suffering through incarceration and carries a social cost to individuals and to the community of which they are a part.

Suspended driving licenses cannot be regained whilst under an order, and mobility is further impaired, affecting ability to maintain employment and education. Breaches of CSOs incur more fines, or lengthening of orders, and become insurmountable problems. It has been reported that in South Australia, many Aboriginal people are imprisoned for breaches of Orders, rather than given other options (Australian Federal Government 1997). Incarceration almost always results in financial hardship, in mental and spiritual suffering, and carries physical social costs to individuals and to the community of which they are a part. The risk of self-harm whilst in custody is particularly acute for Aboriginal people, and Aboriginal males in particular (Australian Federal Government 1997).

Misdemeanours other than those directly related to licensing or driving behaviour that result in a fine or penalty can escalate to a suspension of license if not expiated in the prescribed time. This might be for a behavioural offence such as being drunk and disorderly in a public place, for not paying a parking fine, for having an unregistered vehicle, or other offences.

### 3.4 Education and information material

#### *Department for Transport, Energy and Infrastructure, South Australia*

The following resources are available for download at no charge from the website below. The (South Australian) Driver's Handbook provides information to drivers and riders on their duties and responsibilities on the South Australian road system. The Driving Companion includes information on choosing a driving instructor, the compulsory 50 hour driving experience, competency based training and the vehicle on road test. The Driving Companion is an official record of individual progress in learning to drive, and contains the log book for the fifty hour compulsory supervised driving requirement, competency based training and Vehicle On Road Test (VORT). Information is also available on the Graduated Licensing Scheme, and personal identification requirements.

[http://www.transport.sa.gov.au/publications/reg\\_license\\_permits.asp#drivershandbook](http://www.transport.sa.gov.au/publications/reg_license_permits.asp#drivershandbook)

### **Royal Automobile Association (RAA)**

A computerised test of the material that is based on the Learner's Manual, is available on the following website:

<http://www.raa.net/page.asp?TerID=192&rnd=0.7577293>

### **New South Wales Road Traffic Authority Adult Community Education (ACE) North Coast Driver Education Project**

The On the Road driver education program is online at:

<http://www.drivingproject.org/index.htm>

### **South Australia Police (SAPOL)**

Road safety, Australian road rules, road safety strategies at:

[http://www.sapolice.sa.gov.au/sapol/road\\_safety.jsp](http://www.sapolice.sa.gov.au/sapol/road_safety.jsp)

## **3.5 Discussion**

There was a limited amount of material specific to South Australia, mainly restricted to Learner driver programs. Information from the Criminal Justice System revealed the personal, financial and social costs of driving unlicensed, from which inferences could be made about the resulting effect on the communities to which the individuals belonged.

### **3.5.1 Driver licensing barriers and solutions**

There was a limited amount of material specific to South Australia, mainly restricted to Learner driver programs. Information from the Criminal Justice System revealed the personal, financial and social costs of driving unlicensed, from which inferences could be made about the resulting effect on the communities to which the individuals belonged.

Using South Australia and the Kura Yerlo program as an example, there are enhancements that could add value to an already successful strategy, with the possibility of being transferable to other Aboriginal communities at other locations. In conjunction with TAFE, it may be possible to introduce driver education programs in a nominated community, and link it to other TAFE courses that would lead to better employment prospects and empowerment of Aboriginal individuals and their community. This could become a pilot project, which could be replicated in different regions, in urban, rural and remote locations. It would be feasible to approach discrete communities to assess the need for Learner driver education, and to train one or more currently licensed community members to replicate the Kura Yerlo example. Community capacity and control over this process may enhance the program, encourage participation, and further promote safe community practices and outlooks toward road safety in general. Provision of accredited Learner driver permit testers in each region through TAFE would provide training and employment opportunities for Indigenous people, as well as accessibility to this resource in more remote areas. Further to consultations with the Ngarrindjeri Nation Governance Working Party (representing Indigenous People of the Lower River Murray, Lakes and Coorong) around the development of a Regional Partnership Agreement, the issues of driver license training/assessment issues and access to transport were flagged as topics of interest (Gregory J 2007).

### 3.6 Responding to the needs identified

While it is not appropriate to assume that all Aboriginal lifestyles, outlooks and community needs are the same, it is important to understand the impact on Aboriginal people in rural, remote, and metropolitan areas. A template for Learner driver licensing and practical driver training and assessment that can be adopted and adapted by communities to suit their specific needs will go some way toward addressing the negative health and social outcomes associated with unlicensed driving.

People will be encouraged to make more informed decisions about how and when they travel, about the condition in which they choose to travel, and how they care for their children when travelling. Positive outcomes of conducting several programs simultaneously may be:

- recognition of worth of self and community,
- increased awareness of ability to better enable self and community through means provided by the programs,
- Potential for individuals to become enmeshed with their community through program involvement, where previously individuals and communities have been fractured and in crisis, and
- Increased community capacity through involvement in paid and volunteer positions in programs, potential for TAFE accreditation and enhanced employment prospects.

Sustainability of programs in communities is possible through being community owned and community driven, based on a Community Development model. This would be influenced by the theoretical model developed by Freire (Freire 1993), supplemented with Australian perspectives (Ife 1997; Kenny 2006), and massaged to represent the specific community needs, current and projected capacities.

The Australian Indigenous Road Safety report highlighted the sparseness of research on Aboriginal road safety, and particularly for South Australia (Brice 2000). Brice made several commonsense recommendations, among them:

- for formal links to be made with specialist road injury and safety organisations and emerging South Australian Aboriginal road safety strategies,
- for community research in conjunction with community-based campaigns on road safety awareness,
- that capacity be given to communities to support strategies and make them sustainable,
- that Indigenous scholarship opportunities for researching road safety be encouraged, and
- and that the 1997 report by the Aboriginal Drug and Alcohol Council (Watson, M, Elliott et al. 1997) be updated and used to underpin a forum (Brice 2000).



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## 4 SEAT RESTRAINT NON-COMPLIANCE ISSUES

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### 4.1 Consequences of non-compliance of seat restraints for adults, children and babies, car culture and remedies

In the Northern Territory, fatalities for unrestrained occupants of cars was 68% for Indigenous people, and 46% for non-Indigenous people in the period 1996-99 (ATSB 2004). An interview study of crash involved and control drivers in Auckland, New Zealand showed that a greater than ten fold increase in injury was correlated to seatbelt non-compliance at time of crash, even after adjusting for numerous potential confounders (Blows, Ivers et al. 2005). The same study also found that habitual non-seatbelt users were likely to be unrestrained in crash involvement.

Studies have shown the efficacy of front facing child restraints in providing vital protection in frontal, and in side impact collision situations when correctly fitted (Bilston, Brown et al. 2005), using best anchorage methods, and the child correctly restrained. Other studies have highlighted the dangers and risk of injury and death through child seat restraint misuse, invalid installation, and inappropriate size of child in relation to restraint device (Lalande, Legault et al. 2003; Krahn D, Barker R et al. 2007). A study of the use of child car restraints in Aboriginal families in the Perth area found that 52% of a sample of 209 respondents nominated a wrong restraint type for 3-4 year olds, and an alarming 76% nominated an incorrect restraint type for 5-8 year olds (David Hides Consulting Group Pty Ltd 1998). The same report found that in practice, a relatively low proportion of children were using restraints appropriate to their age and weight, with some children in each age group using an adult seat belt, or not restrained at all (David Hides Consulting Group Pty Ltd 1998).

In April 2000, a promotion to raise awareness of the value of car restraints and to increase compliance in wearing restraints was launched in South Australia ('Buckle Them Up - Aboriginal Seat Belt Campaign'). The campaign was aimed at the Pitjantjatjara community in the remote northwest of the state, with Transport SA producing a resource kit in Pitjantjatjara language and also in English (Brice 2000). The kits contained a video, pamphlets and promotional posters (Transport SA 2000). In conjunction with this package, a "Train the trainer" program was delivered to staff in areas of health and service provision to Aboriginal people, to Aboriginal women, and to Aboriginal children, who then transfer the information to their clients (Transport SA 2001). It was intended that this would be an ongoing initiative, with expansion of the program to Pt Lincoln, Ceduna and the Riverland and other regional areas in 2001 and beyond, but have not rated a mention in any annual report since 2001 (Transport SA 2002). It has been confirmed through personal communication that there is no current promotion around Aboriginal car restraint use (Trevor Bailey Senior Project Officer Transport SA 2005), although the bilingual pamphlet resources are available on the Transport SA website (Transport SA 2000).

The discontinuation of this programme appears to have real consequences in 2005, and not only restricted to the remote location of the APY Lands. It was learnt that transporting parents with infants and children who had travelled down for treatment from homelands and remote areas was problematic for the service because of a lack of familiarity with, and distrust of seat restraints. Commonly, the children had never been restrained before, and being often already distraught, fatigued from lengthy travel and showing anxiety from their exposure to the healthcare system, refuse to be restrained. The driver would seat them safely and depart, the child would cry and become distressed, the parent would unbuckle them and comfort them on their lap, the bus driver would have to stop, and the process would start all over again (Wanganeen 2005). In Perth, nearly 70% of survey respondents reported that their child did not remain restrained for the entire journey, and about 10% of respondents felt that children were safe to travel when being held by another

passenger, and some believed that more than one child in an adult seat belt was safe (David Hides Consulting Group Pty Ltd 1998).

It is apparent that recognition of the safety value of child car restraints, availability and affordability of the units, and accredited installation to ensure correct usage are all critical issues, and that there is a need for action, particularly in the more remote communities.

The 'Buckle Them Up - Aboriginal Seat Belt Campaign' resource is currently being reviewed with the intention to bring the information up to date with the current Australian Road Rules on seat restraints (see Sections 3.3.3 and 3.3.6).

## **4.2 The legal requirements**

As of September, 2006, the Australian Road Rules (Part 16, Rules 264-267 (Office of Legislative Drafting 2006)) state that drivers must wear seatbelts, and that passengers sixteen years or older must occupy a seat fitted with a seatbelt. A child under one year old must be fastened in a suitable child restraint, and must not be positioned in the front row of seats if the motor vehicle has two or more rows of seats. Children between one and sixteen years of age must be fastened in suitable restraints, or wearing a properly fastened seatbelt (depending on age and size of child). Children are not permitted to co-occupy a seat belt or seating position with another passenger. The motor vehicle driver is responsible for the compliance of all passengers. Some exemptions from these rules apply in certain situations (Office of Legislative Drafting 2006). The 2006 Road Rules also specify that travel is not permitted in or on parts of motor vehicles that are not primarily designed for passenger or goods carriage, that the area must be enclosed, and that the seating position must be weight and height appropriate, and also be fitted with a seatbelt (Section 16, Rule 168 (Office of Legislative Drafting 2006)). This effectively bans riding in open load spaces such as utes and truck tray tops, and also constitutes an offence if these conditions are breached. Although all states and territories agreed to implement the above rules, the passing of the legislation will vary between jurisdictions, and interested persons should check with their state or territory to confirm the date of passing of this legislation.

## **4.3 Accessibility of appropriate seat restraints**

Seat restraints complying with the Australian Standards are available for sale from discount department stores, from specialist baby and children's outlets, and from some motoring goods outlets. Correct selection of the appropriate restraint for the individual child is paramount, as is the need for the restraint to be correctly fitted to properly installed anchorage points. In South Australia, Red Cross operates a baby capsule and seat restraint sales and hiring service, which includes free installation by qualified fitters. The restraints and fitting service are available at the following Australian Red Cross safety stores:

31 Sir Donald Bradman Drive, Mile End Telephone: 8443 9700

317 North East Road, Hampstead Gardens Telephone 8367 9765

In the regional and remote areas of South Australia, there is little accessibility to information on restraints, and to the equipment.

### **4.3.1 Changing restraint type as children grow**

It is most important for infants and children to be monitored as they develop and grow, to ensure that the restraint in use is appropriate for the weight and size of the individual. For example, infants

are recommended to be restrained in backward facing restraints until 8-9kg in weight. For larger children, care must be taken that their head is not higher than the back the restraint, which could lead to injury in a collision.

An evaluation of a child restraint provision and monitoring project in the United States found that there was efficacy in using a community health care centre as the contact point for asking whether a restraint was in use, checking for correct installation, and checking that the restraint was correctly fitted to the child and used as intended (Quinlan, Holden et al. 2006). The study found that a high proportion of infants and children were not restrained at the time of contact, and that for those who were restrained, misuse of the system was high. The pilot study supplied systems where needed, corrected installations and educated parents and care givers on correct usage. A follow up several months later showed a significant improvement in presence and correct usage of restraints (Quinlan, Holden et al. 2006). The

In the western Sydney suburb of Mount Druitt, Mr. George Shearer, (Aboriginal Road Safety Coordinator, NSW Road Traffic Authority) and Ms Elaine Gordon (coordinator of the Daruk Aboriginal Health Service), established a child restraint service within Daruk. In brief, the RTA provided funding and structure to implement a restraint hire service, developed an evaluation of community child restraint knowledge (survey), wrote reporting guidelines, funded a restraint fitting service, and funds for a logo, stickers and promotional posters produced by the clientele of the health service. Below is the text from the promotional poster:

“All kids need to be in the right child restraint to travel safely. They will help keep your kids safe, particularly if they are in a crash. There are different types of child restraints including baby capsules, front facing car seats and booster seats.

Having the right restraint for your kids to travel in can be a bit confusing and expensive. The Daruk Aboriginal Medical Service can help sort out the right restraint for you now, and as your family grows.

To keep the mob travelling safely, for a small hiring fee and transferable deposit, the Daruk Aboriginal Medical Service is offering baby capsules for newborns and front facing car seats for children up to five years of age. These restraints will be fitted, checked and regularly cleaned at the centre. And you can return the seats and restraints you have and swap them over as your kids grow.” (Daruk Aboriginal Health Service clients 2005)

The concept of the right of children to be transported safely described on the poster, the recognition of difficulties that go with providing that safety, and the solution to the problems is a template that could easily be transferred to other Aboriginal communities.

## **4.4 Educational and information material**

### ***Australian Red Cross, South Australia***

Brochures from the DTEI are available from the safety store, as well as personal advice on the correct standard and most suitable restraint for the infant or child. Accredited fitters are onsite to install the restraint free of charge, on purchase or hire. Information is also on the website below:

<http://www.redcross.org.au/sa/safetyStores.htm>

### ***Department for Transport, Energy and Infrastructure, South Australia***

The website below has information on legal responsibilities and approved restraints. Brochures are also available for distribution. Some information is available in Pitjantjatjara language also.

[http://www.transport.sa.gov.au/safety/road/road\\_use/restraints.asp](http://www.transport.sa.gov.au/safety/road/road_use/restraints.asp)

As referred to in Section 3.3.2, a seat restraint compliance campaign called ‘Buckle Them Up - Aboriginal Seat Belt Campaign’, is aimed at Aboriginal communities, and specifically for the Pitjantjatjara communities in the APY Lands. The kit was developed by the SA Department for Transport, Energy & Infrastructure in 2000. It consists of a VHS tape, a seat restraint poster and a vehicle information poster for trainers, and a range of brochures. The video has a version in English of 4.30 minutes duration, and a corresponding version in Pitjantjatjara language. It was filmed by Aboriginal community members, and has strong messages about the impact of injury and death from road transport accidents on communities, and emphasises the need to care for children in cars. Ms Bernadette Donaldson, Regional Manager – Retail for Australian Red Cross (SA), kindly reviewed the resource kit with me to ensure correct current versions of restraints were displayed. Since its production in April 2000, the information on child restraints for the 14-26kg group has been superseded. The information on the 8-18kg restraints still just meets criteria, but could benefit from updating. This applies to the brochures for those restraint types as well as the posters and video. For all printed material in the resource kit, the contact details and telephone numbers need to be updated, as some are no longer correct.

**Note:** this recommendation was developed following proceedings of the 3<sup>rd</sup> Indigenous Road Safety Forum, Broome, September 2006, and was adopted by the National Indigenous Working Group, auspiced by the ATSB. A taskforce has been formed (2007) to action the recommendation.

## **4.5 Discussion**

### **4.5.1 Seat restraint non-compliance issues**

Many things influence use of seat restraints, among them knowledge of legal requirements, beliefs about safety, accessibility and affordability of restraints, correct installation of the restraint and fitting to the child, and progression through range of suitable restraints as the child grows. There is also often a belief that the child is ‘safe’ when held by an adult (David Hides Consulting Group Pty Ltd 1998; Wanganeen 2005).

### **4.5.2 Seat restraint non-compliance barriers and solutions**

The provision of infant and child vehicle restraints, installed by accredited fitters, will be a major step forward in protecting a particularly vulnerable, and valued, portion of Aboriginal communities. In combination with positive reinforcement about nutrition and eating habits from community members through the proposed Breakfast Club, the Peer Education Program, and support for youth through the Save A Mate program, safety in travel is likely to improve. People will be encouraged to make more informed decisions about how and when they travel, about the condition in which they choose to travel, and how they care for their children when travelling. Positive outcomes of conducting several programs simultaneously may be:

- recognition of the ability and responsibility of adults to protect children,
- knowledge and means to implement safe travel for infants and children through the Car Restraint Program
- Increased community capacity through involvement in paid and volunteer positions in education and fitting programs, car restraint hire and cleaning service, potential for TAFE or Red Cross accreditation and enhanced part time employment prospects

Sustainability of programs in communities is possible through being community owned and community driven, based on a Community Development model. This would be influenced by the theoretical model developed by Freire (Freire 1993), supplemented with Australian perspectives (Ife 1997; Kenny 2006), and massaged to represent the specific community needs, current and projected capacities.

## **4.6 Responding to the needs identified**

The National Indigenous Road Safety Working Group (NIRSWG), auspiced by the ATSB, has formed a taskforce to review, recommend updates, secure funding, and reissue two major audiovisual kits on road safety and seat restraint education, both featuring Aboriginal people in the development and delivery of the materials. This is a major and necessary step to ensure that road safety resources for Aboriginal audiences is current, has had community engagement, and is culturally acceptable and relevant. This work is not yet complete, and will rely on sufficient funding to produce a comprehensive resource.

Free expert product advice, access to affordable seat restraint hire and professional fitting is an issue actively pursued by the Australian Red Cross (SA). Two safety stores exist in the metropolitan areas of Adelaide, from which this exact work is carried out. Initial discussions have commenced around the provision of like services in rural and remote areas, utilising existing agencies as partners, with Red Cross training and accreditation and administration support. Further work is necessary to culminate in a physical presence of car safety equipment and consumer service in the outlying areas.

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## 5 ABORIGINAL HEALTH

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### 5.1 The Yanangu experience: remote area with strong traditional culture

Western medical structures are alien to Aboriginal culture. They are designed for the majority population and urban populations. There is little room for family involvement, which is at the heart of Aboriginal culture. The focus is on the task at hand, medical procedures, and on the individual. Transport systems within the health are designed in the same way and even the Aboriginal organisations like Stepdown and the Aboriginal Health Services are limited by the culture of the bodies that fund them.

Travelling to health services, especially tertiary treatment centres, has become a daunting experience for many Aboriginal people and their families.

The Yanangu experience of renal disease following relocation and interruption of traditional mobility is a striking example of the links between culture and health. At the heart of the problem is the need to meet traditional responsibilities and to be in the right place for health and community connection.

“... All those sorrowful people, they’re living in town with too much worry, getting sick at (name of hostel), living in one place, not going to Kintore and their family’s not seeing them. Sitting outside, they’re looking for their family, becoming lonelier and lonelier. They then just go back inside their room and think, “My family isn’t coming from Kintore.” 12 (Rivalland 2006) Pg 13

“...Because it was another place. Many of their family died, like young brother, sister, auntie and many old women and many others. Staying too long, we lost our grandmothers and grandfathers. All those first people died in Papunya, in another place.” (Rivalland 2006) Pg 14

Aboriginal people also want to be understood by non-Indigenous health workers and staff who support their treatment:

“Alongside strengthening family relationships, including non-Indigenous WDNWPT staff and transport in trips such as hunting had several intended outcomes. It is important in remote areas to ensure that vehicles are reliable, particularly through extremes of weather when carrying children and those with chronic illness. However such trips also assisted the development of necessary personal relationships required to provide secure cross-cultural care, especially when staff are out of their personal and institutional safety-zones in remote communities. Yanangu regard this as part of their relationship responsibility to make others ‘understand’ (kulini): “Us two went everywhere together ... All of us went for pura (bush tucker) – we were always eating it, by the bucket-full! I finally took her to see my outstation, to show her so she’d understand. (Rivalland 2006) Pg 44

Yanangu emphasised that to remain healthy, all family members must sustain fundamental relationships with ngurra, walytja and tjukurpa. Alongside simple visits, there is a need to be present for funerals, a major opportunity for both renewing acquaintances, being with family and ensuring that vexed issues arising from ritual ‘Sorry Business’ are handled appropriately.” (Rivalland 2006) Pg 37

The importance of connection to land and culture is also noted by McCoy. His focus is on the impact on the young of dislocation and interruption of extended family ties.

“It is not uncommon today, in the desert and other places, to hear a young Aboriginal person say, ‘I’ve got nobody’, or ‘nobody boss for me’. One interpretation of such statements is that they reflect, ‘the rhetoric of personal distinctiveness and autonomy’ (Martin 1993).<sup>30</sup> however, some adults in the Kutjungka region would interpret them differently. They would say, ‘he wants someone to look after him and care for him’. And while they link the cause of the anger and the feelings of hurt to the absence of a parent, or whoever who was responsible for caring for that young person, their understanding is that they are hearing a ‘cry for help’. They would then argue that a new holding experience needed to be introduced for this young person.” (McCoy 2004)

The impact of culture is not just limited to more traditional people or the remote regions. While many less traditional Aboriginal live different lifestyles, the underlying importance of family connection and connection to place is profound.

## 5.2 Aboriginal culture and Western medical culture

Travelling to health facilities, especially in patient facilities, represents a separation from culture and entry into a strict hierarchical structure which is often hostile to Aboriginal culture. People who are vulnerable because of illness are often separated from important supports:

“Most Aboriginal people have experienced a family member going to the city and not coming back. These experiences may, in part, contribute to clients delaying medical visits with their health problems. However, having agreed to travel, on arrival clients’ fears increase and the needs of any accompanying family may not be met, thus escalating the stress as highlighted in the two quotes below. This can be particularly devastating if the illness is life-threatening”. (Stamp, Miller et al. 2006) 2006 Pg 4

“The following situation could lead to serious consequences. With minor variations clients and GPs described similar scenarios in the main study. ... for the patients...you can talk up for them. I mean, I had to check on a PATS claim for a traditional man and find out if he went to his appointment so I could claim it back and they said well he walked into outpatients, now he had gone on the bus, I don’t know how he got from the bus to the appointment, but I said to them, “well did he see the doctor”? And they said, “oh no, he turned around and walked out again.” He probably didn’t know what it was there. No-one was there to meet them. At the very least Cabcharge (taxi vouchers) may help, but this is not easily obtained.” (Stamp, Miller et al. 2006) Pg 5

The Patient Assisted Travel Scheme (PATS) system, while offering some benefits clearly has limitations. The Aboriginal service that is designed to assist with transport and accommodation also had limitations

“There are issues with accommodation as well, so these are really serious problems because people won’t fly if they feel uncomfortable .... Yes, it’s just a problem getting clients to the city. And it is the same as on the bus, sometimes they have to make their own way from the bus to the hospital and because they get in at 6 o’clock in the morning, there is nowhere for some people to go. So they get a bit funny about going.”(Stamp, Miller et al. 2006) Pg 4

There are also restrictions around the use of the Stepdown service:

“People who stayed with relatives in the city became ineligible to use Stepdown when a policy changed. This was an issue much repeated by clients and health workers alike and caused great disruption.” (Stamp, Miller et al. 2006) Pg 6

It is not just the immediate patient that has needs at times of family illness and distress. Little attention is paid by health facilities to the need of the family to travel to meet their support obligations.

“For relatives, dealing with the shock of learning of a family member’s illness and the lack of privacy and respect for personal space within the hospital setting caused needless suffering and the experience of shaming. Visitor limitations also caused distress.

And when we all travelled down in the car after, yes it was really hard to sit down and talk, like we already had the news that she had terminal cancer before we left here, but as soon as you go in there, they are in a room with about five or six other people, and then you just have to pull the blind around and natter away, you sort of sit there, it was really uncomfortable. The situation was really uncomfortable for her husband to sit down next to her because as soon as he saw her he burst into tears and because he is a traditional man, initiated man, he said, he got up shamed like, and walked out. I chased him up and said “look it’s... don’t be embarrassed to cry you know, it’s good to let your emotions out”, because she was in a room with other white people and that as well, and he just didn’t know how to....It is, they are all close together, very close and ...you haven’t got the privacy. You say something and that was when we showed emotions, you know. And they would show it, and it might offend the person next to you or whatever, they might not understand. And this does happen you know. I mean when they are in the intensive care part, there are little rooms that can only have about 4 people in at the max around the bed because the machines are everywhere hooked up to the ceiling. And you have some in there, some outside the door you know, and then we have nurses say “We can’t have that many in here”...that’s family, that’s a son, that’s a daughter, that’s the other son, you can’t chuck them out.” (Stamp, Miller et al. 2006) Pg 7

The association of travelling and hearing bad news in an environment where there is insufficient respect for Aboriginal culture and the needs of families, reinforces a reluctance to move from the familiar home territory and the place that sustains well being.

“A common theme was reluctance to travel to the tertiary hospital from the remote community. Clients feared finding themselves in an alien environment often without an accompanying family member and the support of their kinship structure.”(Stamp, Miller et al. 2006) Pg 9

Culture and history generate barriers to access often resulting in late treatment at a more critical stage.

“Traditionally, Australian and many other ‘developed nation’ health services have relied on the individual delivering himself to the system and largely delivering himself up to the system.”(5) As health practitioners we need to recognise the unspoken paradigms of our culture and how our conditioned expectations and beliefs, however unconscious, do effect our interactions and make us sometimes inaccessible to cultures of a different understanding. We are a product and reflection of western culture, and even the physical spaces we occupy, which we expect to confer a sense of safety, expertise, and technological science, clash directly with the indigenous sense of healing.

Hospitals and large buildings are seen as a threat; bad experiences of the past are associated with large buildings, for example police investigations, community welfare taking children away” (Boustany 1999) Pg 2

## **5.3 Aboriginal health needs**

### **5.3.1 Major population health needs of Aboriginal people in South Australia**

The Aboriginal view of health is holistic. Lack of health is indicated not only by the presence of disease but also disruption and stress in Aboriginal society. The Australian Bureau of Statistics National Aboriginal and Torres Strait Islander Social Survey of 2002 (ABS 2004) paints a picture of this broader need across Australia. The report illustrated the extreme level of disruption in the lives of Aboriginal people, and how the effects vary between urban, regional and remote areas. High levels of poverty, social disruption, violence and injury were of particular interest in the survey, with about 30 % of Aboriginal people reporting difficulties with transport, and a higher than



expected rate of hospitalisation for transport related causes. Many more hospitalisations occur than expected with the greatest differentials being for kidney disease, endocrine and metabolic disease (including diabetes), diseases of the skin, infectious and parasitic diseases, respiratory system disease, injury and poisoning, circulatory disease including heart disease), mental and behavioural disorders and complications of pregnancy.

Aboriginal peoples' reports of their own health are presented in a joint ABS/AIHW report

“Indigenous people were more likely to report fair or poor health than non-Indigenous people at all ages, with the exception of those aged 18–24 years (graph 7.2). The proportion of Indigenous people reporting fair or poor health increased with age, from 8% of people aged 18–24 years to 56% of people aged 65 years or over. Indigenous Australians living in remote areas were less likely to report fair or poor health (22%) than those in non-remote areas (27%).”(ABS/AIHW 2005) pg 93)

In 2005 The South Australian Aboriginal Health partnership published data on a wide range of health indicators of Aboriginal health and mapped them for the Indigenous geographic regions of South Australia (South Australian Aboriginal Health Partnership 2006). This study compared the health indicators in each region with the State Aboriginal average which for the first time showed the large differentials in Aboriginal health in different regions. The document is extensive and would provide a sound basis for detailed planning. The main findings were that:

- Aboriginal people in rural and remote areas had significantly different patterns of disease than their counterparts living in more densely settled areas. In general their risks were higher and in remote areas, diseases associated with poor environmental conditions (e.g. infectious and parasitic disease) were more prevalent,
- It was notable that where chronic health problems which required intensive specialist treatment caused Aboriginal people to relocate forming clusters near treatment centres. This was especially the case for renal disease and mental health and alcohol problems,
- CDEP played an important role in providing income to Aboriginal families, without CDEP, the number of persons dependent on each income was greatly increased, and that
- Very different patterns of health were shown for different areas. There is a need to respond to health needs locally and to understand the cause of the patterns of disease and to provide a wide range of inputs including income, improved access to treatment and environmental improvements.

From the national and state data it is clear that there are some health problems that form a very heavy burden on Aboriginal society in South Australia. The literature on these problems has been sifted and the dynamics of each of the following issues assessed:

- Renal disease
- Heart disease
- Violence and suicide
- Youth and child health
- Injury

### **5.3.2 Renal disease**

Renal disease is a major cause of death and disruption in the lives of Aboriginal people. It is a silent but deadly killer up until it is too late to halt the damage.

“Chronic kidney disease (long-term and usually irreversible loss of kidney function) has impacts on quality of life, use of health services, health expenditure and mortality, but it is difficult to determine how many Australians are affected. Because of a lack of specific symptoms at the early stages, the diagnosis of chronic kidney disease is often delayed or missed. However, it may lead to serious illness and death from complications or co morbid conditions before it is even detected.” (AIHW 2005) p xi

Aboriginal people have much higher rates of renal disease than non-Aboriginal people

“Kidney damage, indicated by protein in the urine, is common among Indigenous Australians, and rates of treated end-stage kidney disease have been found in some communities to be up to 30 times the rates among other Australians (Spencer et al. 1998)”.(AIHW 2005) Pg 90

In 2003–04, there were around 83,000 hospitalisations of Indigenous Australians for chronic kidney disease and its sequelae, 43% of which were hospitalisations of Indigenous males and 57% of which were hospitalisations of Indigenous females. There were nearly nine times as many hospitalisations for Indigenous males and 16 times as many hospitalisations for Indigenous females as for other Australian males and females respectively. The greatest difference between observed and expected hospitalisations for Indigenous males and females were for diabetic nephropathy (11 and 24 times as high) and for care involving dialysis (9 and 17 times as high). Of all hospitalisations for chronic kidney disease and its sequelae, the majority (81,983 or 98%) were for care involving dialysis (ABS/AIHW 2005) pg 108

The Australia and New Zealand Dialysis and Transplant Registry (ANZDATA) keeps records of persons with end stage renal disease.

“In 2003, 6.5% (882) of the 13,625 persons registered with ANZDATA were identified as Indigenous Australians. This is a much higher proportion than the 2.4% Indigenous representation in the total population. Indigenous people commencing ESRD treatment were substantially younger than non-Indigenous Australians commencing ESRD treatment. About two-thirds (63%) of Aboriginal and Torres Strait Islander people registered with ANZDATA were aged less than 55 years, whereas less than half (46%) of non-Indigenous Australians registered were below that age.” (ABS/AIHW 2005) p105

Eventually renal dialysis is necessary for many renal disease sufferers. This treatment requires either peritoneal dialysis which is undertaken only in certain hospitals or fully dialysis which requires machines overseen by highly specialised doctors and technicians. In some area satellite dialysis units supported by electronic communication to main centres have been established to permit Aboriginal people to be dialysed in their home region but this is the exception rather than the rule. The number of dialysis patient is growing steadily.

There is an increasing incidence of renal disease resulting in renal dialysis. It is notable that the number of people involved is relatively small when compared to the high number of hospital admissions shown earlier. This is because dialysis occurs several times per week for many patients.

“Aboriginal and Torres Strait Islander people, particularly those in remote communities, face many barriers to access to health care. These barriers impact on all stages of CKD, affecting the prevalence and management of risk factors and diseases associated with CKD, detection of kidney problems, management of CKD and prevention of disease progression. Treatment for ESKD is a particular problem for Australians living in remote communities. The distance to the nearest health facility with the necessary equipment for dialysis may be hundreds or even thousands of kilometres, and the cost of travel and accommodation may be prohibitive. In addition, the cultural importance of family and place to Indigenous Australians means that the thought of leaving their home and moving to a hospital or satellite dialysis facility which is too far away for them to return home easily or for family and friends to visit is distressing and frightening to many patients (Willis 1995).” (AIHW 2005) Pg 93

“Why Indigenous peoples have such an excess risk of ESKD is largely unknown. The three main causes of ESKD in Aboriginal people are diabetic nephropathy, primary glomerulonephritis, and hypertension.<sup>4</sup> A much larger proportion of ESKD in Aboriginal Australians is attributed to diabetic nephropathy (47%) as compared with non-Aboriginal Australians (17%); however, the ESKD excess is not explained solely by differences in diabetic prevalence or comorbidities.<sup>1</sup> The causal chain contributing to chronic kidney disease (CKD) may start at or before birth, with maternal factors,<sup>5</sup> low birth weight and reduced nephron mass<sup>6,7</sup> rendering the kidney more vulnerable to diabetes and hypertension. Marked regional differences in ESKD have been noted between Aboriginal populations<sup>8</sup> and in ethnically homogeneous countries such as Japan, suggesting socio-demographic influences rather than genetic predisposition are responsible.<sup>9</sup> Environmental factors such as isolated living and socioeconomic disadvantage may play the more important role in the development of CKD”  
Haysom et al 2007 Pg 1

Haysom’s study showed that there were no environmental or racial predictors of kidney disease in young children, suggesting that factors in later life were responsible. The study finds that

“A number of health conditions are associated with renal disease including cerebrovascular disease, lung disease, peripheral vascular disease, coronary artery disease, smoking and diabetes. In 2003, most of these conditions were reported in similar proportions for Aboriginal and Torres Strait Islander and non-Indigenous patients beginning ESRD treatment. Diabetes however was much more likely to be reported for Aboriginal and Torres Strait Islander patients than for non-Indigenous patients (70% and 27% respectively). The greater excess of diabetes among ESRD Indigenous entrants reflects the burden of this disease in the Aboriginal and Torres Strait Islander population. In 2003, diabetes was attributed as the primary cause of ESRD for more than 55% of Indigenous dialysis patients compared with 18% of non-Indigenous dialysis patients (Excell & McDonald 2004).

A number of other factors have been associated with renal disease, including low birthweight, reduced renal volume in childhood, occurrence of childhood post streptococcal glomerulonephritis, obesity, alcohol use, repeated bacterial infections and hypertension. These have all been implicated as factors contributing to the higher incidence rates of ESRD among Indigenous Australians (McDonald & Russ 2003).” (ABS/AIHW 2005) 14 pg 107

Kidney disease is a growing burden on Aboriginal people. It generates a need for transport because of the complex nature of treatment in the more advanced stages and the fact that treatment of this nature is not available locally. It is unlikely that the need for complex treatment will fall in the near future.

“Standardised ESRD incidence among Indigenous Australians is highest in remote regions, where it is up to 30 times the national incidence for all Australians. In urban regions the standardised incidence is much lower, but remains significantly higher than the national incidence. Forty-eight per cent of Indigenous ESRD patients come from regions without dialysis or transplant facilities and 16.3% from regions with only satellite dialysis facilities. Conclusions: There is marked regional variation in the incidence of ESRD among Indigenous Australians. Because of the location of treatment centres, there is inequitable access to ESRD treatment services for a significant proportion of Indigenous patients.” (Cass, Cunningham et al. 2001) pg 24

The impact of renal disease and the need for alternative strategies to provide alternative services has been documented by Rivalland:

“In the NT there is a hidden cost burden in taking people to services rather than services to people. There are very stark and obvious examples of this type of cost burden when people in need of care are taken to urban centres for treatment. In many cases they are followed by extended family, stays become indeterminate and associated with the added social costs of homelessness, alcohol and drug abuse, and at the same time there is a negative impact on the community from which they come. Banskott Report 2003” cited in (Rivalland 2006) P 2006

Rivalland notes throughout his report that transport is a key factor in increasing the health of the community and in breaking the cycle of disruption – disease – disruption. With renal disease, the need to lessen the community impact of the disease through distribution of treatment and recognising the impact of relocation and family travel by supporting culturally sensitive transport.

### 5.3.3 Heart disease

Cardiovascular disease covers the circulatory system but in Aboriginal people the most evident type of this disease involves the heart.

“Compared with other Australians, Aboriginal and Torres Strait Islander people were considerably more likely to suffer a heart attack, to die from it without being admitted to hospital, and to die from it if admitted to hospital. In hospital they were less likely to receive key medical investigations or common procedures such as coronary bypass surgery or angioplasty. It was also found that Indigenous Australians admitted to hospital for coronary heart disease (CHD) were more complex cases, but this does not appear to account for differences in procedure rates. Specifically, compared with other Australians, Indigenous Australians had:

- 3 times the rate of major coronary events such as heart attack
- 1.4 times the out-of-hospital death rate from CHD

and when in hospital:

- more than twice the in-hospital CHD death rate
- a 40% lower rate of being investigated by angiography
- a 40% lower rate of coronary angioplasty or stent procedures
- a 20% lower rate of coronary bypass surgery.”

(AIHW:, Mather et al. 2006)

In an urban study of the Australian general population, Ingerfield et al argued the importance of immediate access to hospital care when it is likely that a cardiac event has occurred. Clearly for many Aboriginal people access to such care is impossible and given the cultural issues described earlier, the likelihood of delay is great.

“The Australian National Heart Foundation and the Cardiac Society of Australia and New Zealand recommend that patients with chest discomfort for longer than 10 min should be taken to hospital by ambulance for urgent assessment. However, previous studies have found lengthy delay time, with common median time of one or more hours from the onset of symptoms to seeking medical assistance. Twenty-five per cent of those having an AMI die within the first hour of symptoms and the benefits of therapies such as thrombolysis and stenting are time dependent.” (Ingerfield, Jacobs et al. 2005)

Many patients with chest pain did not consider themselves seriously ill and waited considerable time before seeking hospital medical care. Consulting a GP before presenting to hospital resulted in further delay. Often relatives, friends or GPs made the decision to call for an ambulance. Patient and general community health education should continue to emphasize that chest pain is a potential medical emergency and an ambulance should be called before calling a GP. GPs should consider developing an action plan to manage those patients presenting with chest pain. (Ingerfield, Jacobs et al. 2005) pg 222

It is notable that heart disease is more prevalent in rural and remote areas. This presents difficulties for responding to critical events in a timely manner.

“While a majority of heart failure may occur among people living in cities (because that is where most people live), a disproportionate number of cases occur among people living outside these cities (due to age and other socio-demographic risk factors) where services may be fewer and less accessible.” (Clark, McLennan et al. 2005) pg 2

Aboriginal people experience a high rate of heart disease with high levels of mortality. Brown and Blashki note the frequency of heart disease and the cultural roots for its existence and like the AIHW report the lack of access to adequate preventive and emergency treatment.

“Cardiovascular disease (CVD) is the primary cause of death for the Aboriginal and Torres Strait Islander population with approximately three times the age adjusted CVD death rate when compared to the non indigenous population.<sup>8</sup> The premature nature of cardiovascular deaths is also of concern, with 62% of all cardiovascular deaths occurring before the age of 65 years, compared with only 10% among non-Indigenous Australians. The greatest mortality differentials occur between 25–54 years of age, where the rates are 7–12 times that of non indigenous populations” (Brown and Blashki 2005) Pg 814

The transition from ‘traditional’ to contemporary lifestyles has been noted as a likely antecedent to the high rates of CVD, renal impairment, impaired glucose tolerance and diabetes among Australian Aboriginal populations. Traditional risk factors have been noted to be more common among Indigenous Australians than among their non indigenous counterparts. However, there is growing interest in the role of socioeconomic and psychosocial factors in the disproportionate burden of CVD experienced by Indigenous Australians. Given that social factors influence the risk of coronary heart disease (CHD), the excess CVD mortality in indigenous populations is most likely to have its foundations in economic, social, physiological, psychological, and educational disadvantage. (Brown and Blashki 2005) Pg 814

“Access to a range of clinical and preventive services. Indigenous Australians predominantly utilise publicly provided health care services,<sup>40</sup> and underutilise the Pharmaceutical Benefits Scheme, Medicare Benefits Schedule, specialist services and general practitioner consultations.<sup>41</sup> In particular, access to specialist cardiology services, appropriate interventional diagnostics and acute care modalities is limited in remote and regional areas where large indigenous groups reside.<sup>42</sup> There is also evidence to suggest that even when health care facilities are available, Aboriginal people are less likely to receive cardiac procedures than non-Aboriginal people during hospital admission.<sup>43</sup> Indigenous Australians are also more likely to access public hospitals for acute mental health care,<sup>44</sup> often at a time of crisis, with disproportionately low access to community based mental health care,<sup>23</sup> and private specialist mental health care.<sup>45</sup> They are over-represented in rural and remote settings where mental health services are poorly distributed.” (Brown and Blashki 2005) Pg 814

The Royal Flying Doctor Service (RFDS) is the main supplier of emergency retrievals in rural and remote areas. While this minimises the time to initial treatment, there is often no room for family to accompany patients. Family must arrange travel by other means. The health clinic needs to respond to both the medical crisis and the impact of the crisis on the community, but is often under resourced (Peiris, Wirtanen et al. 2006).

An adequate treatment to heart disease requires transport services that deliver a range of healthy foods, access to early diagnosis and treatment, and emergency response once a cardiac event is suspected. In addition access to ongoing treatment through primary medical care and support through primary health care means that practitioners need to access communities.

### **5.3.4 Violence, suicide and self harm**

Literature on violence suicide and self harm has been grouped together because there are common underlying causes and the events are often linked within the community. The most recent literature

on violence focuses on family violence because it covers a wide range of violent outcomes in Aboriginal society.

“Family violence is a serious issue for Aboriginal and Torres Strait Islander peoples in Australia. Violence in the Indigenous population is a ‘multi-dimensional problem that manifests itself in a range of health and related social outcomes’ (Anderson 2002:409). ‘Violence is perceived by many people, both Indigenous and non-Indigenous, as a major problem in Indigenous communities’. In addition, ‘the incidence of violence in Indigenous communities is disproportionately higher in comparison to the same types of violence in the Australian community as a whole’ (Memmott et al. 2001:6). Violence is a significant cause of morbidity and mortality in Australia’s Indigenous population, with women predominantly being the victims. According to Oberin (2001:25), ‘domestic and family violence has an even more major impact on Aboriginal and Torres Strait Islander women than it does on other groups of Australian women’. In addition, Bagshaw et al. (2000:123; cited in Women’s Services Network 2000:8) state that ‘considerable evidence exists which suggests that Indigenous women are far more likely to be victims of domestic violence than non-Indigenous women and they sustain more injuries’. The context in which violence in the Indigenous population occurs differs from that of the non-Indigenous population. According to Mow (1992) domestic violence in Indigenous communities can only be understood in the context of the historical, political, social and cultural environments in which it occurs (cited by Astbury et al. 2000:429). Historically, the poor treatment of Aboriginal and Torres Strait Islander people in Australia is considered an underlying factor in the extent to which violence occurs in this population today. This is supported by Oberin who states that ‘the high rates of domestic and family violence in Indigenous communities must be seen in the context of colonisation, disadvantage, oppression and marginalisation’ (2001:26).” (AIHW, Al-Yaman et al. 2006)

Data on the prevalence of violence come from the 2002 National Aboriginal and Torres Strait Islander Social Survey. About one in four Aboriginal or Torres Strait Islander people aged 15 years or over reported being a victim of physical or threatened violence in the twelve months before the survey (24%). The rate was higher among those who:

- were aged 15–24 years
- had been removed from their natural families (38% compared with 23% among those not removed)
- had a disability (29% compared with 22% among those without a disability)
- had experienced a high number of stressors (50% of those with 11 or more stressors compared to 8% among those with none)
- lived in low income households (27% compared with 19% among those in high income households)
- were unemployed (38% compared with 21% among the employed).

The age-standardised rate for being a victim of physical or threatened violence among the Indigenous population was over twice the rate of the non-Indigenous population. Although the rates were similar among those living in major cities (25%) and in remote areas (23%), people in remote areas were much more likely to report that family violence was a neighbourhood problem (41% compared with 14% in non-remote areas).

People who experience family violence may seek refuge, especially women. In 2003–04, 7,950 Indigenous females sought refuge to escape family violence. Indigenous females and males were 13 and 7 times more likely to seek this assistance as non-Indigenous females and males, respectively. The rate was highest for females aged 25–34 years (ABS 2004).

In 2003–04, there were 4,500 hospitalisations of Aboriginal and Torres Strait Islander persons due to assault in Queensland, Western Australia, South Australia and the Northern Territory combined.

Indigenous females and males were 35 and 22 times as likely to be hospitalised due to family violence-related assaults as other Australian females and males, respectively. Indigenous hospitalisation rates for family violence-related assault were highest among:

- females
- people aged 25–34 years.

For Indigenous females, about one in two hospitalisations for assault (50%) were related to family violence compared to one in five for males. Most hospitalisations for family violence related assault for females were a result of spouse or partner violence (82%) compared to 38% among males.” (AIHW., Al-Yaman et al. 2006) pg ix-x

There is increasing understanding of the causal factors of violence.

“The framework presented in *Violence in Indigenous communities* (Memmott et al. 2001) divides the causes of violence in Indigenous communities into the following three broad categories:

1. Precipitating causes—particular events that precede and trigger a violent episode by a perpetrator.
2. Situational factors—circumstances in the social environment of the antagonists.
3. Underlying factors—the historical circumstances of Aboriginal and Torres Strait Islander behaviour.

Memmott et al. (Memmott, Stacy et al. 2001) argue that the violent dispossession of land and continuing cultural dispossession of the past 200 years have resulted in particular social, economic, physical, psychological and emotional problems for Indigenous people, which is reflected in the high level of violence in their communities. This view is supported by Gordon (Gordon, Hallahan et al. 2002) in *Putting the picture together: inquiry into response by government agencies to complaints of family violence and child abuse in Aboriginal communities*. The report finds that colonisation has resulted in an ‘unresolved grief that is associated with multiple layers of trauma spanning many generations’. Some of these ‘layers of trauma’ include: colonial aggression; genocide; racism; alienation from tribal lands; breakdown of social structure; loss of spirituality and languages; removal of rights and responsibilities; labour exploitation; and large-scale removal of Aboriginal children from their families (‘stolen generations’). These and other factors have contributed to the erosion of social structures and traditional values, and a range of social problems in current Aboriginal communities (Memmott, Stacy et al. 2001). While these social problems have their roots in the physical trauma and violence that were inflicted on Aboriginal people, they are themselves also a cause of violence.

High unemployment, low socioeconomic status, poor housing and overcrowding, poor health, high mortality, poor governance in local communities, and a lack of support services are all likely to contribute to the higher levels of conflict and violence.” (AIHW., Al-Yaman et al. 2006)

“The Cross Borders Domestic Violence Service is an initiative of the Ngaanyatjarra Pitjantjatjara Yankunytjatjara (NPY) Women’s Council. It covers a region of 350,000 square kilometres across border regions in Western Australia, South Australia and the Northern Territory. The NPY Women’s Council developed the cross border service, ‘Good Protection for All Women’, in 1994 in order to provide protection for Aboriginal women experiencing domestic violence. Aboriginal women within these communities experience severe levels of violence in circumstances where there are few support services and tremendous geographical isolation, not to mention enormous cultural barriers. The service provides opportunities for women to talk about their experiences of violence and abuse, information about domestic violence and support options, ongoing advocacy and liaison with services, practical assistance including financial resources, access to medical services, transport and accommodation. The establishment of cross border protocols on policing has been critical to positive legal outcomes as three different states’ legislation and different police practices are encountered by the service.” (Greer 2001) Pg 12

Early intervention requires good transports for the services, the ability to remove victims and perpetrators to safe accommodation and to return people to their support systems. Violence can also be self inflicted:

“The subject area of self-harm, parasuicide and suicide among Aboriginal Australians is one of persistent and overwhelming tragedy marked by expressions of pain, disconnection and despair. Australian Bureau of Statistics data revealed that, for the 1998–2001 period, Aboriginal Australians had much higher rates of premature death due to external causes (16% of all deaths) than the total Australian population (6% of all deaths).<sup>1</sup> Of all external causes, which include accidents, intentional self-harm and assaults, premature death due to deliberate self-harm accounted for 33% of male deaths and 15% of female deaths. Studies of the occurrence of deliberate self-harm and suicide in rural Aboriginal communities have been undertaken since the mid-1980s when the increasing occurrence of male deaths by suicide was noted in rural areas, such as the Kimberley (Northern Territory) and rural and urban South Australia”. (Proctor 2005) pg 237

More recent studies have connected the identified risk factors for attempting and completing suicide, such as high alcohol use, mental illness, relationship breakdown and disrupted parenting, to broader social, historic and economic issues.<sup>10</sup> Hunter’s analysis pointed to the crisis experienced by many Aboriginal communities after changes to legal, social, political and industrial arrangements which previously characterized many rural Aboriginal communities before the 1960s. For many rural communities, poverty, unemployment, poor housing, high alcohol consumption, economic dependency, the incarceration of parents and family members, and interpersonal violence has become common social experiences. (Proctor 2005) pg 238

The response to violent crises needs to be readily available and designed to be in line with Aboriginal culture. It will vary according to the location and the local Aboriginal culture.

“Crisis intervention strategies in indigenous communities might include: \_ identifying groups at high risk; \_ identifying referral options, including grief or trauma counselling; \_ developing crisis intervention teams in the community – the team approach alleviates strain on individual caregivers; \_ developing safe, efficient transportation for clients and caregivers; and \_ developing a family violence crisis hotline run by volunteers” (McTimoney 1994) p.24. (Blagg, Ray et al. 2000) p19

“The multi-agency team includes tribal councils, community representatives, the judiciary, police, health and social workers. The teams devise protocols for investigating abuse and handling individual cases, and signatories to the protocols agree on an investigative and follow-up system. Protocols include practical issues such as transport, costs, equipment and use of facilities. A diversity of agencies are encouraged to adopt the protocols, depending on whether there are issues of child sexual abuse, elder abuse, etc, in addition to violence between intimate partners”. (Blagg and Valuri 2003)Pg 20



“Services and other practical forms of assistance to victims may take many forms, including legal advocacy, crisis care, trauma debriefing, assistance with transport, financial assistance, medical services, accommodation, translating services, and so on.” (Blagg and Valuri 2003)Pg 30

The response to violence depends on adequate and immediate access to appropriate service and the removal of barriers to free movement during the crisis and resolution phases. It is necessary to acknowledge the extent to which extended family issues are involved and to include people beyond the immediate victim and perpetrator in the resolution process.

### **5.3.5 Youth and child health**

Aboriginal demography shows a large and increasing proportion of young people. If they are to experience greater health than the older generations it is necessary to ensure that they receive supportive and preventive services. It is beyond the scope of this review to cover the full range of issues in child and youth health. Selected issues have been review to illustrate the breadth of the strategies needed.

#### ***Maternal and peri-natal health***

While maternal and peri-natal health has improved significantly, there is still a great deal that can be done. Many births of Aboriginal babies are to mothers younger than the Australian average (ABS 2006), and the pre birth health of the younger mother may not always be at a premium.

“Between 1997 and 1999, Indigenous status was recorded for 75 (83%) of the 90 maternal deaths during childbirth. Seven deaths were of Aboriginal and Torres Strait Islander mothers, accounting for 9% of the deaths where Indigenous status was known (Slaytor, Sullivan et al. 2004). The maternal mortality ratio for Aboriginal and Torres Strait Islander women was approximately 24 per 100,000 confinements in 1997–99 and is more than three times as high as the maternal mortality ratio for other women (7 per 100,000 confinements). These rates must be interpreted with caution due to the very small number of Indigenous maternal deaths. (ABS/AIHW 2005) pg 78”

Indigenous birthing services with community outreach have been recommended to support Aboriginal mothers (Carter, Lumley et al. 2004)

#### ***Nutrition***

Over time, dietary changes in Aboriginal people’s lives have been associated with higher levels of obesity, renal disease, and Type II diabetes, which were previously at low levels where the more traditional high protein, high fibre diet was prevalent (ABS/AIHW 2005).

Diet and nutrition are particularly important to Aboriginal and Torres Strait Islander people for a number of reasons.... Aboriginal and Torres Strait Islander families living in isolated areas face particular challenges in providing their children with affordable, healthy food on a regular basis. Poor nutrition in the early years of life can affect childhood development, growth and health. Inadequate vitamin and nutrition intake, especially in the preschool years, can affect immune function and increase susceptibility to illness, disease and infection (Tomkins 2001) in (ABS/AIHW 2005) pg 82

#### ***Health risk factors and social and emotional wellbeing***

Many factors influence the health and wellbeing of Aboriginal people, and some factors are exacerbated by where people live. Family and household factors include stressful events in the family, overcrowded living conditions, experience of violence, hospitalisation, death of family

members, physical health of those in the household. Children of members of the Stolen Generation, who had endured separation and dislocation from family and country were found to have higher risk of social and emotional disruption (Zubrick, Silburn et al. 2005). In A Western Australian survey, regular smokers were found to be at higher risk of clinically significant emotional and behavioural problems than Aboriginal people who were non-smokers, and smokers of marijuana had an increased risk of those same problems, compared to non-users of marijuana (ABS/AIHW 2005). The same report also found that participation in sport had a positive effect on social and behavioural outcomes, and that being subjected to racism had a negative effect on social integration and group behaviour (Zubrick, Silburn et al. 2005). Suicidal ideation and suicide attempts were found to be higher in young girls than in young boys, and young Aboriginal people who had been exposed to family violence were more likely to seriously contemplate, or attempt, self harm (Zubrick, Silburn et al. 2005).

Of those who reported having had suicidal thoughts in the 12 months prior to the survey, 39% also reported having attempted suicide in the same period. Aboriginal young people who had been exposed to family violence were more than twice as likely to have thought about ending their own life (22%) as those who had not been exposed to family violence (9%). A much higher proportion of Aboriginal boys with low self-esteem (21%) had thought about ending their own life than those with high self-esteem (ABS/AIHW 2005) pg 85-86

### ***Injury***

Aboriginal safety has been identified as a key health issue. The Aboriginal safety strategy supports wide ranging interventions to improve the environment and opportunities for young Aboriginal people National Public Health Partnership (National Public Health Partnership 2005).

In an assessment of Aboriginal youth health needs Lyon writes

“In some ways, the health problems of Aboriginal young people are similar to those of non-Aboriginal young people. They both have problems that come from learning about sex and taking risks, especially with drugs (which includes consuming alcohol and tobacco, and sniffing petrol and other substances). They also don’t care much about their own health.” (Lyon 1992) Pg 3

She also notes that

Motor vehicle accidents are high on the list of the causes of death, as they are for Aboriginal adults. Petrol sniffing is a major cause of death among Aboriginal youth in some remote areas. While these causes of death are a worry, it is important to say that doing risky things that can kill them is not something that only young Aboriginal people do. When some Aboriginal youths are reported to be drinking and driving, drinking and fighting, sniffing petrol, and dying in high speed car chases, they are taking the sorts of risks that teenagers and young adults do in many parts of the world, not just Australia. Violence between young men may appear to be more of a problem among Aborigines because ritualised swearing and fighting is part of the traditional Aboriginal way of resolving conflicts in many parts of Australia. Unfortunately, culturally approved and “controlled” physical force may turn into a wrong kind of violence under the influence of alcohol and other drugs. Much of Aboriginal illness and death is related to the way people live, and can be prevented. Young people may not have these problems yet, but it is likely they will have some of them if nothing changes. (Lyon 1992) p4

Youth and child health then covers a wide range of issues and factors. There is a need to ensure that safe travel is available for young Aboriginal people and their care givers and that service are accessible. Transport for Aboriginal people and support workers is critical to reducing the burden of poor health in the coming generations.

## 5.4 Health services and treatment responses for Aboriginal people

How do health services respond to prevention, primary health care, acute care and chronic disease? The expenditure on health and the distribution of health and related services are critical issues in determining transport needs.

Health expenditure patterns are summarised by the AIHW:

“Aboriginal and Torres Strait Islander peoples comprised 2.4% of Australia’s population.

- Total expenditures on health services for Aboriginal and Torres Strait Islander peoples were estimated at 2.8% of national health expenditures, having risen from 2.6% in 1998–99. Estimated expenditure on health for Indigenous people rose markedly, from \$1,356.1 million in 1998–99 to \$1,788.6 million in 2001–02.
- Average expenditures per Indigenous person were estimated at \$3,901 in 2001–02. That was 18% more than the \$3,308 per person spent on the non-Indigenous population. However, because Aboriginal and Torres Strait Islander peoples relied heavily on publicly funded health care providers, government expenditures were much higher for them than for other people—\$3,614 per person compared with \$2,225, or 62.4% more. The relatively small differential between average health expenditures on Indigenous and non-Indigenous people reflects both differences in the volume and mix of health goods and services provided to the two groups and differences in the average costs of providing those services. A greater proportion of the Indigenous population live in remote and very remote regions where service delivery costs are greater, but the types of services that they access, on average, involve lower costs. For example, while their average rate of separation from hospitals is about double that of non-Indigenous people, lower-cost interventions, such as dialysis, make up a larger proportion of those separations than in the case of non-Indigenous people.
- The Australian Government provided 43.1% of the total funding for Indigenous health expenditures, the state and territory governments provided 49.5% and 7.3% came from non-government sources, including out-of-pocket payments. The corresponding figures for non-Indigenous people were 47.8% from the Australian Government, 19.5% from the states and territories and 32.7% from private sources.
- An estimated 70.5% of expenditures were through programs managed by the state and territory governments; 23.4% were through Australian Government programs; and the remaining 6.2% were for services that were essentially the responsibility of non-government providers.

•Hospital services, of all kinds, accounted for 47.5% of Indigenous health expenditures, compared with 34.2% of the spending on other people. Community health services and public health activities, including those through Aboriginal Community Controlled Health Services (ACCHSs), absorbed another 24.6% compared with 4.5% for non-Indigenous people.” (AIHW 2005) p xvii

Comparative trends in health care expenditure are also important.

“A number of factors should be noted when reviewing changes over time, including that the methodology for developing estimates has changed, the Australian average reflects variations in jurisdictional expenditure and the actual figures may be higher or lower than the estimates published in this report. Thus, caution should be exercised when interpreting changes in expenditures over time.

- Given these reservations, the ratio of Indigenous to non-Indigenous estimated expenditures per person in 2001–02 (1.18:1) was marginally lower than in 1998–99 (1.22:1). This reflects the faster expenditure growth in the types of health services of which Indigenous people use less (such as those funded through private health insurance).
- Estimates of average expenditures per person for Indigenous Australians increased in real terms by 16.9% between 1998–99 and 2001–02. This was lower than the increase for non-Indigenous people of 18.8% over the same period.
- Indigenous people were low users of mainstream medical and pharmaceutical services covered by Medicare and the Pharmaceutical Benefits Scheme. Per person, Medicare benefits for Indigenous people were 39% of the non-Indigenous average and PBS benefits were 33%.
- Expenditure on services provided to admitted patients in acute-care hospitals represented over half (52.5%) of state/territory expenditure for Indigenous Australians, lower than for the non-Indigenous population.
- Indigenous Australians were also low users of private dental and other professional services and of privately provided health aids and appliances. A possible contributor to the low rate of expenditure in these areas was the low rate of coverage by private health insurance—only about 15–20% of Indigenous people had private health insurance cover.
- Although the regional analysis was limited to a number of major programs, there was evidence that a combination of higher usage and costs resulted in much higher expenditures on Indigenous people in the outer-regional and remote/very remote areas than in the major cities. And the hospital use data accorded with it. At 489 per 1,000 population, the overall rate of acute hospital admissions/separations for Indigenous people was 45.0% higher than for non-Indigenous people. There was little difference between the two population groups in the cities, but in the outer-regional and remote areas Indigenous separation rates were between 87.7% and 165.2% higher. Hospitals played a much different role for Indigenous Australians in those areas. “ (AIHW 2005) p xvii

Patient transport costs are identified separately. Per capita Aboriginal Patient transport costs (\$136.95) are almost three times those of non Aboriginal costs (\$47.09) (AIHW 2005) Pg 7. Approximately 80% of these costs are borne by State and territory governments (AIHW 2005)

The APTW project specifically focuses on South Australia.

“The South Australian Government’s expenditure on health for Aboriginal and Torres Strait Islander peoples during 2001–02 was estimated at \$61.0 million (Table 5.7). This accounted for 4.2% of the State Government’s recurrent expenditure on health of \$1,460.0 million, compared to the Indigenous population proportion of 1.7% for the State. Estimated expenditure on acute-care hospitals (\$36.5 million) accounted for almost two-thirds (59.8%) of the Government’s total expenditure on Aboriginal and Torres Strait Islander peoples. The majority of this (\$30.0 million or 49.2%) was through expenditure on admitted patient services in acute-care hospitals. Community health services constitute the next largest Indigenous expenditure item at \$9.0 million, followed by non-admitted patient services at \$6.5 million. Average expenditure per person on health for Aboriginal and Torres Strait Islander peoples was estimated at \$2,388.43—2.5 times that for the State’s non-Indigenous people, which was estimated at \$941.33 per person. Per person, average expenditure for Indigenous people was greater than for non-Indigenous people in respect of all the major categories in South Australia (Figure 5.6). For admitted patient services in acute-care hospitals, it was \$1,174.54 for Indigenous Australians, compared with \$512.51 for non-Indigenous people. In the case of community health services, an average of \$353.75 per person was spent on Aboriginal and Torres Strait Islanders—more than four times the rate for non-Indigenous people (\$86.53).” (AIHW 2005) p45

Aboriginal health service patterns show higher use of community health services and lower use of general practitioners. Higher than expected use of acute care services but underutilisation of

advanced preventive procedures. This pattern appears to result in cost shifting of health care from the Commonwealth to the State.

#### **5.4.1 The geographic distribution of health services**

Transport needs are strongly influenced by the comparative distribution of the health services and the people who use them. Recent trends in health planning have limited the spread of specialist treatment services and facilities. The focus is on efficiently providing for the majority of the population in South Australia as a whole. This is as we have seen above is an ageing urban population. The young Aboriginal population with strong rural connections needs a different service distribution. Even in urban areas, there is likely to be a mismatch between services and needs that results in increased distance to be travelled to receive appropriate care.

The Health and Welfare of Australia's Aboriginal and Torres Strait Islander Peoples 2005 considers a number of indicators (AIHW 2005) that show how services match Aboriginal populations in discrete communities:

- 43.8 % of discrete Aboriginal populations are 10 km or more from the nearest hospital and 25 km or more from the nearest community health centre,
- Only 47.5% of remote dwelling and 64.4% of non remote dwelling Aboriginal people in Australia had access to a motor vehicle to drive, and
- 16.4% of remote dwelling and 9.8% of non remote dwelling Aboriginal adults indicated that they cannot get to the places needed. A further 18.5% in remote areas and 8% in non remote areas said they could not easily get to the places they needed to go. (ABS/AIHW 2005) p183

Health expenditure data provides an insight into the relative costs of providing health services in different types of region. It is clear that rural and remote health care costs are higher for public acute care services across the board and that this differential is far greater for indigenous patients. General practitioner costs are shifted to public primary health care programs and the private hospital sector is notable for its absence of service to Aboriginal people especially outside of major cities.

In South Australia, health services for country regions are planned through a single country health division while the metropolitan area is divided into two planning regions, north and south of the CBD. Each region considers its population and health needs as defined by hospital admissions and health survey data. Aboriginal health has a state wide focal group and a directorate in each of the health areas. There is a strong government focus on the APY lands and a general commitment in the State government Strategic plan to improving Aboriginal Health.

The Aboriginal controlled health sector offers services in Ceduna, Port Lincoln, Cooper Pedy, the APY lands and Mt Gambier and there are specialist government health units in Whyalla, and Port Augusta (covering the northern parts of the state, and in several localities within the metropolitan health regions including Muna Paendi, Enfield and Port Adelaide in the northern suburbs and Noarlunga in the south. This sector focuses on primary health care.

#### **5.4.2 Patient travel schemes**

People who live more than 100 km from the treatment required can be assisted by the Patient Assisted Travel Scheme PATS. For Aboriginal people Stepdown provide a linkage service connecting with transport accommodation and treatment.

“Working alongside PATS, Stepdown provides a link-up transport service from airports and bus or train stations to accommodation and/or medical services for Indigenous clients and approved relatives coming in from rural and remote areas. However, they do not collect clients who are staying with relatives in the city.

PATS is subsidised at \$AU30, but this amount can be hard for clients to find and is only the beginning of the expenses incurred. Already disadvantaged families, most on low incomes, are placed under huge financial pressure, for despite the existence of PATS, the associated expenses for a trip to the city can amount to hundreds of dollars. For example the cost of hostel accommodation for the client and accompanying family members who travel to and from the hospital is high and not subsidised. Emergency financial assistance is critical because of basic essential costs. “ (Stamp, Miller et al. 2006) p5

The PATS system and Stepdown are not always easily accessible. Payment of travel costs is made after a successful contact with the treatment facility has been undertaken. Health service often subsidise patients with the hope that they will receive the PATS rebate, but when things go wrong the service is left out of pocket.

“Discussions demonstrated that Stepdown is under duress and does not operate an out of hours service. Formal Stepdown notification timeframes could not be met in emergencies, which could result in very sick patients arriving with nobody to meet them, with potentially serious consequences.

Well, see with Stepdown you’ve got to give them 24 hours notice, and a lot of time we don’t have 24 hours notice here, because it’s an emergency. And the only way our patients can get out is either we fly them out on the night plane or the next morning plane or stick them on the bus that night. That’s a 12-hour trip and then no-one will meet them at the other end.

Travelling with an escort, although ideal, does not always happen:

Some people we send down, next thing we get a phone call saying that we need someone down here, he’s only got 24 hours to live and whatever. A family member needs to be down there so they can go through all this stuff. “(Stamp, Miller et al. 2006) p6

In remote areas it is necessary to use air travel. Planes are often equipped only to take patients and family support is not possible. Often emergency treatment is provided by air one way, but return travel is by other means such as bus services. This places great stress on people who are sick and disoriented and when travelling alone patients often are unsure where they are or how they will connect to their community when they get off the bus.

One remote health service running a renal program reported on the high costs of air travel and the importance of other means of travel for family and community members.

“Travel by planes formed 76% of the total cost. WDNWPT noted the importance of vigilance and coordination required to keep a lid on this particular cost area, especially with recent aviation fuel price increases. The observation has been made by WDNWPT staff that ‘Return to Country’ visits might be particularly important in the early period following commencing dialysis, as Yanangu try to set recent chaotic events into some kind of sustainable perspective.

Over the last 12 months, 50% of visits by car now use private vehicles, supported by the use of fuel vouchers, comprising around 55% of total vehicle journey costs. This development seems a particularly cost-effective way to assist those on dialysis who have decided to continue to live on nearby home communities to Alice Springs (Ikuntji, Hermannsburg, Santa Teresa), and travel to town 3 times/week. Currently they are compelled to be dependent on relatives or supportive PHCS for transport assistance. In contrast however, the much longer dirt road to Kintore (travel time 6–7 hrs) is arduous, and so far marked by the crosses of three individuals killed returning from visiting relatives on dialysis. WDNWPT estimates the total cost of ‘Return to Country’ for all its’ members now at around \$50,000/yr, including coordination.” (Rivalland 2006) p38

### **5.4.3 Supports for families**

While patient travel schemes provide much needed assistance for patients, their operational strategies are far from generous and under current policy they cannot deal with the need for non patients to travel. In emergency situations liaison service are often unable to respond, and important opportunities for intervention are lost.

The focus of health services is almost entirely on the patient. There is little recognition of the need for family support and families are rarely in a financial position to be able to travel at their own expense.

Aboriginal cultural literature however stresses the importance of family support systems and point to the early termination of care or reluctance to attend care in the absence of support.

### **5.4.4 Support for the Health system**

The health system often relies on generic transport services. These arrangements can change quickly with no consideration of the impact of the change on health and environmental services.

In 2006 the collapse of an air transport services to the APY lands had major implications for health services in the region.

“An Aboriginal health group expects the collapse of a regional airline will cause the delay of blood tests and doctors' appointments. Many remote communities in South Australia's far north relied mainly on Aboriginal Air Services (AAS) to transport medical supplies and patients. The Darwin-based consortium will cease operations from today. Nganampa Health Council spokesman John Singer says flights to the APY Lands have been reduced to one a week.

"People are going to have to be flying in, have their appointment but then have to stay in town for an extra week for the returning flight the following week," he said. "So that'll cause a whole lot of problems for our patients and also with our clinic staff, with the pathology, all the samples and all the tests that they do that needs to go into Alice Springs will also take longer." Mr Singer says several communities are seeking alternative transport. "We're also looking at what other public transport system we can get in place on the lands, whether they look at Transport SA around a public transport system like a bus service across the lands," he said. "But we won't be able to just rely on that one flight we need to have something else to support that as well." AAS helped deliver mail, medical supplies and patients to remote communities in the Northern Territory, Western Australia and South Australia.”

<http://www.abc.net.au/news/australia/sa/summer/200609/s1742681.htm> accessed 2/5/2007

Environmental health management requires specimens used for testing water for bacterial contamination to be transported under reliable refrigeration. Road transport over long distance and rough roads can make this difficult and the standards of testing in remote areas especially can be compromised. Overall, the health system requires adequate and safe transport systems to operate effectively, but these are by no means guaranteed.

## **5.5 Aboriginal mobility and health care**

### **5.5.1 Interaction of mobility and continuity of care**

Aboriginal people are often highly mobile. There have been few studies of this mobility but Aboriginal health services often service large numbers of people who are not resident in the area where the service works but are visiting or staying short term. The most recent study reports on the remote area of Queensland, but it is likely that the findings can be used to better understand movement in South Australia in the absence of specific local studies.

Mc Dermott P et al 2006 argue that Aboriginal mobility in remote areas follows a systematic pattern. They note the reasons for travel and the implication of travel on housing:

“The lives of Aboriginal people in rural and remote Australia are characterised by marked inter- and intra-community mobility, with circular movements within a ‘mobility region’, and a high rate of travel to places (including regional centres) within the region for relatively short periods of time.

- The most common period of a visit was two to three days or less and most visits were for less than one month. The highest frequency of visits to one place was an average of 39 trips per year per visitor by Alpururulam men to Mt Isa.
- Kinship is the main driving force of Aboriginal mobility. Kinship is maintained through mobility, kinship makes mobility possible, and kinship contributes to the definition of mobility regions. The distribution of an individual’s kin generates for an individual a ‘beat’ – a set of places, which he or she can visit and expect to obtain hospitality and economic support if necessary.
- Other drivers of spatial mobility patterns in the study area include sporting events, recreation, hunting, collecting bush resources, and shopping. • There were some differences in the spatial patterns of the mobility of the male and female participants in both Alpururulam and Dajarra, with Dajarra female participants travelling to a less diverse number of settlements.
- Visits lead to additional wear and tear on houses, with small houses accommodating high household numbers likely to require more frequent maintenance than would otherwise be the case. This is simply due to the natural wear and tear associated with high use by a large household.” (Mc Dermott P et al 2006 Pg 1)

They also note the interaction between the distribution of service and the need for road transport.

“Without the decentralisation of services, Aboriginal people are likely to continue to travel to access services. Both the Dajarra and Alpururulam residents make regular visits to Mt Isa as their regional service centre. Such mobility has implications for the safety and economy

In the wet season, Alpururulam experience major difficulties with the transportation of both medical patients and bio samples due to the unsealed access roads and airstrip. This in turn places increased pressure and cost on the Mt Isa (and Townsville) hospital due to patients waiting longer than necessary to return home”. (Mc Dermott P et al 2006 Page 5

The wide range of reasons for travelling is also described in the table from Mc Dermott et al Pg 93 2006 shown below.

It appears that Aboriginal mobility follows a predictable and systematic pattern, influence by family and kinship responsibilities and to varying extents links to land and place. This contrasts sharply to the patterns of non Aboriginal society and it appears that it is this cultural difference that makes mainstream transport options less available to Aboriginal people. This cultural clash issue is made worse by racism among transport operators and non Aboriginal passengers for example de Crespigny et al 2002 reported:

“The women also highlighted safety issues in relation to transportation options. Some felt unsafe using public transport at night. One had found it safer to sit close to the driver when she was on buses or trains because then other people did not harass her if they were drunk. She continued, however:

...but being of Aboriginal descent, you know... non-Aboriginal people don’t really harass me in any way because they sort of know that when you get off at the train station there will be other black fellas there, so they don’t harass no black fellas on the train.” (de Crespigny, Groenkjaer et al. 2002) p18

And



Another participant experienced discrimination when taking taxis, as the drivers would ask to see her money before allowing her in their cab. This participant found such behaviour, rude and offensive. She had also experienced a taxi driver picking on her daughter:

wasn't drunk! was merry. A cab driver picked on my daughter... Sal started screaming and cursing at him. And because he told her to get her feet off the seat and she was sitting in the front. And she never had her feet on the seat Yeah. And he said you might put shit on my shoes ... you might have shit on your shoes. And she was ... four. (de Crespigny, Groenkjaer et al. 2002) p17

Travel for Aboriginal people, whether for health care or social or cultural reasons represents a great challenge. Transport patterns are quite different to non- Aboriginal society but this is not recognised in State Transport policy or provision. Transport policy recognises the different needs of urban and regional or remote regions.

South Australian Transport policy urges a move toward integration in regional and remote areas.

“Access to services is not an issue just for the aged in the community. It is also an issue for youth, the unemployed, single parents and those who do not drive or own a car. Access to services is exacerbated for people residing in regional (particularly remote) areas with limited services, where essential services such as health, financial and education are clustered into the larger regional centres. The PTB has found that passenger transport in regional South Australia is provided on a mostly compartmentalised basis to meet a particular client group or need. This frequently leads to inefficient utilisation of the asset and consequent problems with service quality and sustainability. In response to increasing calls for improved services and in recognition of the lack of integration of services, the PTB commenced detailed studies of the travel needs and existing transport resources within regional communities. The aim was to develop a model for integrated passenger transport based on travel expectations and current and future needs of the community. This was within a model for a coordinated whole of government approach to the delivery of services to regional South Australia.” (Webster, Saunders et al. undated) p4

The report goes on to describe a needs based service model that needs to be owned and supported by the community. It concludes that:

“Generally a package of integrated passenger services for a community consists of:

- stand-alone services providing access to major service centres in the region
- feeder services into existing passenger transport services to enable access to major service centres such as Adelaide
- ad-hoc services for the elderly and youth specifically aimed to reduce social exclusion
- services for specific organisations within the community, such as schools and hospitals (Webster, Saunders et al. undated) Page 5

and recommends the following basis for the future:

- The need to move away from thinking about vehicles to services. Rather than focussing on the vehicle, it is first important to determine what services are needed and then how best to provide them.
- Linking different needs and resources into a viable package of services by taking an integrated whole of government and community approach, services can be provided more efficiently, but are also more accessible by the general community, rather than only specific sectors of the community. Additional services can then be provided with social inclusion objectives that wouldn't have been available before.

- A single contractor to provide the package of services efficiently, usually with one vehicle This has also proved to have benefits for the contractor, through increased charter work as well as benefits for the broader community. (Webster, Saunders et al. undated) Page 7)

## 5.5.2 Health need and service availability induced mobility

The mapping of Aboriginal health needs by SAAHP demonstrates that the provision of health services can induce mobility. For example Aboriginal people often move to live near renal services especially when they are in need of dialysis. The provision of mental health support services and an Aboriginal run alcohol treatment service in a country area near Adelaide also appear to be accompanied by an increase in people needing the service residing in the area. Clustering of need near treatment facilities can be demonstrated near the Queen Elizabeth Hospital in Port Augusta and Ceduna.

When health reasons make it necessary for a person to change residence, this often creates a chain reaction. Families move to support the person and the change in family distribution has ripple effects in the extended family.

Patterns of service in the health sector interact with patterns of disease and residence in a complex cultural context. The result at present is inadequate safe transport and inadequate health care for South Australian Aboriginal people.

## 5.6 Discussion

### 5.6.1 Health and transport: a complex issue

This review has only touched the surface of the range of health needs of Aboriginal people. It has attempted to highlight key health issues and identify how these issues impact on the need for Aboriginal people to travel. The major conclusion to be drawn is that lack of adequate transport systems interact with the health and cultural needs of Aboriginal people to produce a situation where a twofold problem occurs. Firstly Aboriginal people often travel unsafely at times of stress and health crisis in the family. Secondly, reluctance to travel induced by lack of access to safe travel contributes to under-servicing of health needs and the continuation poor health among Aboriginal populations.

The review has identified the following issues:

- Transport for Aboriginal people needs to acknowledge and respond to the cultural needs to travel and the importance of family and community support systems. There is a need for increased access to safe transport in all areas but especially in rural and remote areas where greater health needs coincide with poor road systems, lack of publicly funded transport and increased travel distances,
- The nature of health needs and the distribution of health treatment resources generate a need for travel. While there are patient transport subsidies available, they are not able to allow agencies to adequately respond to the needs of Aboriginal people and their families,
- The need to travel by Aboriginal people can be at least partially offset by redistributing health services. These services are highly fragmented with separation of planning for primary medical care, primary health care, specialist consultation and community support services. This results in duplication of travel and higher than necessary transport costs while wasting the resources that are available,

- Transport for Aboriginal people and the goods and services they need have the potential to build connectedness between Aboriginal people and between Aboriginal people and the general community,
- Addressing the lack of transport in rural and remote areas will not be easy but it should be remembered that in South Australia this means addressing the need of 13,000 people,
- In the urban areas, racism, on public transport and taxi services, needs to be addressed,
- There is also a need to recognise that public transport services may not adequately meet the needs of patient and families in times of crisis and that more supportive and private means are required, and that
- Aboriginal society has a different age distribution to Non Aboriginal society in South Australia. Unless care is taken, modifications to health service to meet the needs of the majority population could increase rather than decrease transport problems associated with Health care for Aboriginal people.

## 5.7 Responding to the needs identified

There are hopeful signs in South Australian transport policy that more flexible and appropriate transport systems can be developed on a demonstrated needs basis. At national government level the Coalition of Australian Governments also is working toward better integration between government sectors and government and private enterprise.

The issues identified in this paper need a cooperative multi-sector response and a level of cultural sensitivity not shown so far. Action is required at a number of levels:

- Core policy development that builds the communication strategies necessary for Inter-sectoral cooperation,
- The transport needs of localities with high health needs should be assessed and a coordinated response put in place. This response might include:
  - improvement of road systems,
  - use of shared community transport with accredited drivers in safe, well maintained vehicles to support patients and their families as they access health care and undertake cultural responsibilities such as attending funerals,
  - Coordination of agency personnel's use of transport and freeing up of restriction on non employee travel in agency vehicles,
  - Increasing driver training,
  - Motor vehicle maintenance schemes and safety checks,
  - Advocacy by Aboriginal agencies to ensure that needs are properly understood and that the policy options for the general population will not meet the needs of the younger and more highly stressed Aboriginal population, and
  - Acceptance by government that in order to improve Aboriginal well being that the resources committed should be in line with the high level of need generated by poor health, cultural disruption and geographic distribution of health service.

There are fewer than 25,000 Aboriginal people in South Australia. It should not be beyond the capacity of a modern society to ensure that they can travel safely and experience much improved health.

Aboriginal people represent a minority population that can easily be overlooked when the focus is on a majority urban dwelling ageing population.

Access to health services needs to be increased both by more services travelling to meet Aboriginal people where they are and easier and safer travelling for Aboriginal people with health needs and their families.

Access to safe and flexible transport for Aboriginal people is a key issue that needs to be addressed across multiple sectors. Often however such cross sectoral ventures, due to their complexity generate an overhead that Aboriginal people cannot afford, There is a need for clear leadership and commitment to getting results for Aboriginal people.

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## 6 ABORIGINAL DISABILITY

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### 6.1 What is disability?

There are many different definitions of disability ranging from definitions based on a narrow physical or mental impairment focus to wider definitions that include social disability.

The Social Inclusion Board of South Australia has summarised the definitions of disability used in South Australia as follows.

“There is a range of definitions of disability currently being used in Australia and South Australia as well as quite significant differences in eligibility criteria for programs providing services to people with a disability.

The definition in the South Australian Disability Service Act relies on medical definitions of disability. While this is useful for allocating welfare resources, it has been criticised more recently by some disability advocates, who prefer a human rights based approach, using a social model of disability. This model draws a crucial distinction between disability and impairment. Disability is seen as a social condition; an externally imposed disadvantage or restriction while impairment is seen as a medical condition. Based on this analysis, the barriers which exclude

disabled people from full participation in society are the result of the way the social and built environments are constructed. The problem lies not in the physical impairment but in the way in which institutions and policies fail to meet the needs of people with impairments.

The Disability Discrimination Act 1992 (DDA) definition of disability is very broad and is influenced by the human rights approach. It includes people who have now, did have in the past, may have in the future, or are believed to have a:

Physical;

Intellectual;

Psychiatric;

Sensory;

Neurological disability; as well as covering

Learning Disabilities;

Physical disfigurement; and

The presence in the body of disease-causing organisms

Day Options uses the definition contained under the South Australian Disability Services Act 1993. Education provision falls under the DDA definition of disability due to the introduction of the Disability Standards for Education 2005 where every person with a disability has a right to study at any educational institution in the equivalent way as any other student.

The World Health Organisation (WHO) uses the bio-psycho-social model, recognising that ‘disability’ is a continuum of functioning that all humans experience. They describe disability as a dynamic state of restricted function affected by interaction of the person and activities in which they participate and the environment and personal factors.(de Bats 2003)

The Australian Bureau of Statistics (ABS) relies on self-identification where disability was defined as any limitation, restriction or impairment, which has lasted, or is likely to last, for at least six months and restricts everyday activities.

Although these definitions are not an exhaustive list it does highlight the diverse definitions that apply to disability services and the methods of identification ranging from medical assessments to self-identification. For some service sectors, such as education, new disability types have been added to the applied definition, however the additional types may not be allocated direct services as they fall outside the current resource categories,

There are many people with a disability who do not need nor want specific disability support services in order to make successful transitions from school. There are others who, due to the severity of their disability and the impact it has on them, have a degree of exclusion due to the allocation of resources and support services to particular categories, and

Given the finite resources and the degrees of hardship, encountered by some young people, careful consideration will be required to ensure we get the greatest value from this exercise. An intervention model that considers who may be missing out, and the hierarchy of needs associated with the disability types, will be a useful strategy to determine treatments that are the most effective and efficient. “(Social Inclusion Unit 2006) pp4-5

The definitions used are based on western views of social, physical and mental functioning, but these may not coincide with the Aboriginal views.

In a report on extensive community consultations with disabled Aboriginal people and their associates in New South Wales, the concept of what it was like to be Aboriginal person and to be disabled was discussed. It was found that discrimination had been widely experienced, and that disability added a further layer of discrimination to what they experienced as being Aboriginal, factors also compounded by issues of gender, youth or old age (Aboriginal Disability Network of New South Wales Incorporated 2007). Aboriginal people with less obvious disabilities often are reluctant to identify as disabled, because of this layering effect. Further, the way in which Aboriginal communities viewed their disabled members differed from the wider community view, and was not always as enriched as might be imagined. For example, the report described situations where close kinship ties and solid family support embraced the disabled family member and valued them as individuals, yet basic aids and equipment that would normally be considered a ‘given’ were not accessed, perhaps because of lack of awareness, but also because of a common view of family providing the support, rather than seeking support from outside agencies (Aboriginal Disability Network of New South Wales Incorporated 2007). Dependence on family and kin may have the effect of reducing the visibility of the disabled person, and have the effect of marginalising them within their own community.

## **6.2 Aboriginal cultural factors**

Disability is a culturally defined term. The disability does not rest in the person who is disabled alone, but in limitations to function in the society in which the individual lives. Ariotti argues that there is a need to consider the meaning of disability in Aboriginal culture when interpreting any report on Aboriginal disability:

“At the National Industry Association for Disability Services (ACROD) conference in Alice Springs some years ago, a senior Commonwealth bureaucrat in the disability area made the comment: ‘It’s a waste of time to define disability. There are so many different definitions that it becomes too confusing. You have just got to get up and do the work (provide the services)’ (L. Bannerman, pers. comm., 1993). However, refusing to define disability is in fact a decision to accept the status quo, that is, a decision to accept the most commonly accepted definition: any lack or limitation of competence.<sup>2</sup> This definition is based on the medical model of disability which, as Barton points out, is an ‘homogenised and individualised form of thinking (which) is essentially asocial and depoliticises questions of definition, expectations and practices’ (p. 4).<sup>3</sup> Within such an approach, other relevant factors such as culture, gender, socioeconomic status, history and power relationships are all ignored in the search for a universally acceptable definition. This search fails to take seriously the fact that ‘in many cultures, one cannot be “disabled” for the simple reason that “disability” as a recognized category does not exist. There are blind people and lame people and “slow” people, but “the disabled” as a general term does not translate easily into many languages’ (p. 7).<sup>2</sup> In contrast, the word disability, as it is commonly understood, has been constructed during particular historical circumstances in Europe.” (Ariotti 1999)

She further argues that:

“The particular historical circumstances in Europe that contributed to the social construction of disability have been well summarised by Finkelstein.<sup>8</sup> He postulates that disability is a paradox: on one hand a personal tragedy, passivity and dependency; on the other, a form of group discrimination involving constant struggle and independent action. He argues that the construction of this paradox passed through three historical phases.

(1) Prior to the industrial revolution, disability did not exist because people with physical impairments had a lowly but legitimate role in society. They were ‘cripples who were socially active, asserting their right to live and be in the community’ (p. 10).<sup>8</sup>

(2) Disability was created during the industrial revolution. Able-bodiedness, in the pursuit of higher productivity, became the only acceptable standard. People with disabilities were placed in newly constructed asylums and institutions and became dependent on a growing number of quasi-medical helping professionals.

(3) In the current context, Finkelstein argues that the paradox of disability is resolved because people now recognise that it is ‘the nature of society which disables physically impaired people’ (p. 11).<sup>8</sup> He says a person’s limitations, because of his or her physical impairment and dependency on others, are irrelevant in defining disability, because every person, able-bodied and disabled, is limited in what he or she can and cannot do. ‘Dependency is not unique to disabled people’ (p. 38).<sup>8</sup>” (Ariotti 1999) Page 217

Ariotti develops these themes pointing to how the notion of disability is foreign to the Anangu peoples. She argues that:

- “there is some evidence to suggest that people with impairments were treated and cared for no differently from other members of the group or clan in traditional Aboriginal communities Pg 218
- “There is no word in the Pitjantjatjara language for disability. The tendency was to specify each impairment as it affected the particular organ or sense. In Pitjantjatjara, a person may be kuru pati (blind) or pina pati (deaf) or he/she may witapitjara (have back pain) or lurpani (hobble around), but there was no abstract term that differentiated between or separated people with impairments from the rest of the community. That is, the language indicates that people with impairments were generally accepted as part of the normal composition of the community. Pg 218”
- History, the Pitjantjatjara language and the social structure of the family all suggest that, prior to the invasion, there was no such thing as Anangu cultural recognition of the concept of disability. Pg 218 The European invasion brought the language and concepts of disability “The construction of disability occurs at a number of different levels. First, it occurs at the cognitive level. New words and concepts are introduced to the Anangu which challenge their own Pitjantjatjara language and the way they think about people who are physically impaired. Second, disability is created at the behavioural level. Having been taught new words and concepts, people are now forced, or encouraged, to behave

in accordance with these new ideas. Third, disability is created at the social level. Control over most facets of their lives has been, and still is, wrested from the Anangu by the dominant white society. This disempowerment leads to many individuals with impairments becoming not only disabled but 'dispossessed and displaced, demoralised and depressed' (p. 196)<sup>22</sup> as well as the culture itself becoming 'culturally disabled'.<sup>23</sup> Page 219

- The removal of children with disability and the impact of this by eroding Aboriginal culture through loss of language and knowledge has played a major role in shaping current views in Aboriginal society of disability.
- There is an emerging empowerment phase where it is possible for Aboriginal people to accept aides and treatment in order to improve function without fearing the negative impacts of the European label of disability.

Not all Aboriginal people are Anangu and there is very little literature to describe other views of Aboriginal culture. Nevertheless, Ariotti's powerful discussion signals the need for a cultural debate when the concept of disability is linked to Aboriginal people.

Ariotti concludes:

"The understanding of disability that emerges from this historical process is a dynamic and evolving concept intimately connected with the history, culture and language of the Anangu. It is important that service providers work from a framework that recognises that disability is perceived in broad holistic terms and does not stay confined to the limitations and sense of loss experienced by the individual person. The best way to ensure that this occurs is that all service providers, not just those employed by Aboriginal controlled organisations; accept the directions of and priorities established by the community. Service provision, therefore, must be based on scrupulous attention to the way each individual and community defines disability. In this way, it is the individual and the community and their perceptions of the issues that determine how the services are provided." (Ariotti 1999) Page 21

It is therefore necessary to treat with caution the estimates of numbers and types of disability and to recognise that almost all estimates of need will be based on non Aboriginal definitions and concepts.

### **6.3 Aboriginal disability needs**

The current data on disability is defined within the European context of providing services and making diagnoses. The South Australian social inclusion board uses a broad definition of disability and cites data from the ABS National and Aboriginal survey of 2002.

"In terms of Indigenous people with disabilities, the ABS National Aboriginal and Torres Strait Islander survey of 2002 found 38.6 % of Indigenous South Australians reported having a disability or long-term health condition. Of these, only 25.1% were employed and a further 10.7% were undertaking a Community Development Employment Program (CDEP)." (Social Inclusion Unit 2006) Pg 6

In 2007 the Australian Institute of Health and Welfare reviewed the quality of data and the identification of indigenous status in disability collections. They concluded that while there had been improvement in the identification of Aboriginal and Torres Strait islander peoples, there was a need for further improvement. Data from the report are summarised below but should be treated with some caution as they are likely to underestimate the real level of need.

Apart from the 2002 ABS survey, most of the data available come as a bi-product of service delivery, making it difficult to estimate the number of people receiving multiple services. Services to disabled persons are funded under the Commonwealth State/Territory Disability Agreement CSTDA. From this data collection an overall estimate of disability can be made. "The proportion of Indigenous clients accessing CSTDA-funded services in 2004–05 was 4.9% or lower in all



jurisdictions except for the Northern Territory, where 31.3% of CSTDA clients identified as being of Indigenous origin.” (AIHW 2007)

It is notable that the upgrading of the data collection has seen the estimate of the number of Aboriginal people with disability increase from 125 in 2002 to 563 in 2003-04 and 636 in 2004-05. This demonstrates that underestimation has been a major problem in the past. It is likely that further improvements will be made and the estimates will increase further over time.

The Home and Community Care program (HACC) also provides services to disabled people. Like CSTDA data there has been a problem with the identification of Indigenous status in the past. The most recent data comes from 2004-05.

Age specific patterns of use are available for 2004-05. These show that in South Australia about one third of recipients are less than 50 years of age and two thirds more than 50 years old. IN many aged groups South Australia has high rates per 100 Aboriginal clients.

There is also a description nationally of the types of service utilised. This is based on data from 2004 and provides an insight into the pattern of HACC services used. Domestic assistance, Transport, social support and delivered meals are the most common service provided to Aboriginal people.

Residential aged care services are also considered to be providing for people with disability. It must be remembered that the number of Aboriginal people living to an age where residential aged care services are usually offered is small. In addition the Aboriginal family and community support system and the need for older people to remain in contact with their land influence the uptake of such services. The data below show how few of these services are accessed by people of Aboriginal and Torres Strait Islander descent. In 2004-05 only 17 permanent residential care places were funded for indigenous people in South Australia.

At national level 75% of residential aged care places are in outer regional, remote or very remote areas, possibly reflecting the importance of country to older Aboriginals.

Older people who live in the community are supported by community aged care packages. Once again numbers of recipients are small with only 100 packages provided nationally in 2005.

The emphasis of data collections at national level is on older people. There are relatively few Indigenous older people and this combined with difficulties of identification in data sets and possible cultural mismatch of disability service means that few services are offered.

The general disability data point to less than 700 Aboriginal people receiving services in South Australia under the Commonwealth State agreement. However when a broader social view of disability including access to education and work is taken, as in the Aboriginal and Torres Strait Islander Survey of 2002, almost 40% of 26,000 (about 10,000) Aboriginal people are identified as experiencing a disabling condition in the context of Australian society.

There are significant problems in the field of intellectual disability. As closed head injury related disability and neural damage associated with petrol sniffing are recognised as significant issues, it is important to understand how intellectual function has been changed. The validity of standard tests for intellectual disability within the Aboriginal culture is at best questionable (Wettinger undated). Difficulties with language are known to interfere when tests for intellectual disability are used across cultures in addition such tests are strongly influenced by western views of culture and western expectation of knowledge development.

The Department of Education and Children’s Services (DECS) in South Australia notes:

“Diagnostic processes for disabilities related to cognitive functioning (i.e. Intellectual disability as well as Communication and Language disabilities) pose problems for professionals working with Aboriginal children. The possibility of cultural bias is obvious in tests of intelligence or social and language abilities.

Standard tests are based on expectations of early experiences and learning within a non-Aboriginal culture. The formal test scores of children who have not had these experiences (due to cultural differences or socio-economic disadvantage) will be lower than those who have, with or without the presence of an identifiable ‘disability’. While this is particularly true of Aboriginal children living in remote areas, it also applies to those in country or metropolitan areas whose family life is different from non-Aboriginal culture. English as a Second Language (ESL) and English as a second dialect (ESD) may also contribute to low standardised test scores” (de Bats 2003) pg 37

The committee went on to make a most important point. Failure to identify need results in failure to provide services.

“Given the cultural bias of standard assessment techniques and in recognition of the existing cultural and language differences, some professionals are loath to diagnose Aboriginal students as having a disability, in order to avoid negative labelling. This occurs despite the fact that these students are experiencing difficulties in learning at school. Project participants believed that if all Aboriginal students with learning difficulties were formally assessed, there would be a much higher number verified with disabilities. It was also stated that a minority of teachers persist in the discriminatory belief that most Aboriginal students are slow learners. There is a tightrope to be walked between recognising abilities within a cultural context and not labelling inappropriately, and providing the attention and support that can improve individual learning. In addition, a student may operate at the level of his or her peers within a disadvantaged social environment, but not at a level that is desirable to function well in the broader society.

Not identifying Aboriginal students with disabilities (whether out of benevolence to avoid labelling or from a discriminatory perspective that assumes they are slow learners), results in these students not receiving additional support to improve learning outcomes.” (de Bats 2003) pg 37

Despite the problems and with a view to using what is known, the literature reports on Intellectual disability using standard western assessments, as these are the criteria for the allocation of funding. DECS data indicates the known need of Aboriginal children in South Australian schools.

Glasson et al in a study in Western Australia argues that

“To date, ID in the Indigenous Australian community has received only limited attention, with little available information on its prevalence and causes.” (Glasson, Sullivan et al. 2005) Pg 627

He uses client record information to assess the distribution of Intellectual disability in WA. He concludes that the incidence rate is approximately double that of non Aboriginal people and that much of this excess can be attributed to economic conditions, poor physical environments and associated physical diseases and social and environmental factors such as alcohol use in pregnancy and experiencing assault and physical harm in pregnancy. Most Intellectual disability is detected in early school years but even when detection and initial connection to support services occurs, there are difficulties with maintaining continuing support.

“A large proportion of the Aboriginal cases lived in non-metropolitan areas where appropriate services may be difficult to access. It was disappointing that 30% of cases were recorded as inactive for receipt of services, suggesting either that contact may have been lost with clients living in remote areas or that social or cultural barriers were preventing service utilization. In overall terms, it seems probable that a significant proportion of cases had not been adequately assessed, or was not directed towards appropriate services”. (Glasson, Sullivan et al. 2005) Pg 631

In South Australia education authorities recognise the complexity of dealing with disability

“Many Aboriginal families face multiple social disadvantages. This may include: poverty, unemployment, racial prejudice, domestic violence, gambling, or alcohol and substance abuse. The effects of social dislocation and dysfunction affect the totality of their lives. Limited access to housing and transport produce ongoing stress. The high rate of transience disrupts community involvement and continuity. When these disadvantages are combined with disability, the child and the family will need considerable support” (de Bats 2003) pg 34

The data on Aboriginal disability prevalence must be considered very limited. There are serious issues concerning its validity and its ability to identify Aboriginality. It appears as though the number of disabled Aboriginal people according to the narrower definition if disability is small, but this may be due to the low quality of the data.

The broader definition of disability that includes impairment of access to education and social resources suggest that up to half of the Aboriginal population in South Australia are seriously disadvantaged.

## **6.4 Disability services and treatment responses for Aboriginal people**

In South Australia a multi agency approach is taken to disability based on the wide ranging definition described earlier in this review by the Social Inclusion Board. There are eleven portfolios that have a recognised responsibility. The strategy was developed in 2003 in response to changes in the Commonwealth Disability Discrimination Act:

“The Promoting Independence strategy provides a set of broad strategies under each key outcome area to enable all 11 Portfolios and their agencies to target their efforts and therefore reduce discriminatory practices within Government programs, service delivery and employment. The implementation of these strategies is to be in consultation and partnership with people with disabilities, their associates, service providers and other levels of Government.”

The portfolios and sub departments are:

- Department of Human Services
- Department of the Premier and Cabinet
- Department of Treasury and Finance
- Justice Portfolio
- Department for Administrative and Information Services
- Department for Transport, Urban Planning and the Arts
- Department for Environment and Heritage
- Department of Education and Children’s Services
- Department of Further Education , Employment Science and Technology
- Department of Water, Land and Biodiversity Conservation
- Office of Economic Development
- Department of Primary Industries and Resources SA

Interestingly, while the Department of State Aboriginal Affairs is noted as having a role in the main document, it is not considered in the definition of portfolios responsible for reporting on outcomes. The Department of Sport and recreation which the Social inclusion board sees as being important in the delivery of services to Aboriginal people is also omitted.

“The ultimate responsibility for the achievement of the five key outcomes is with the Chief Executives of the Portfolios. The key outcomes specified within Promoting Independence are:

- Portfolios and their agencies ensure accessibility to their services to people with disabilities
- Portfolios and their agencies ensure information about their services and programs is inclusive of people with disabilities
- Portfolios and their agencies deliver advice or services to people with disabilities with awareness and understanding of issues affecting people with disabilities
- Portfolios and their agencies provide opportunities for consultation with people with disabilities in decision-making processes regarding service delivery and in the implementation of complaints and grievance mechanisms
- Each Portfolio Chief Executive will ensure that their Portfolio has met the requirements of the Disability Discrimination Act 1992 and the Equal Opportunity Act 1984” (Department of Human Services 2003)Pg 7

This strategy is a mainstream strategy and there is only limited reference to Aboriginal people. Indeed in the whole document there are only four references to Aboriginal people. These relate to correctional services and prisons, communication needs in the department of human services, material for Indigenous people held in the Department of State Aboriginal Affairs DOSSA), and the role of:

“... DOSAA which consults with Aboriginal communities on transport and access issues. DOSAA has been actively involved on both the Working and Steering Groups preparing for the forthcoming State Indigenous Disability Conference to be held in Adelaide. It is also a member of the Mental Impairment Indigenous Reference Committee and the Mental Impairment Indigenous Reference Group which address the mental health problems experienced by Aboriginal people involved with the justice system” .(Department of Human Services 2003) Pg 51)

Service and policy foundations are multi-sectoral and profoundly mainstream. Aboriginal disability issues hardly show up on the policy radar.

When transport and disability strategies are considered, there is clear recognition of the importance of transport for the disabled.

“The Department for Transport, Urban Planning and the Arts (DTUPA) ensures access to services by people with disabilities through implementation of its Disability Action Plan. The Action Plan ensures that the needs of people with disabilities are considered at all levels of service development, implementation and provision.

This approach recognises the skills and expertise that people with disabilities can contribute to the identification of barriers and their removal within the transport portfolio’s responsibilities.

The contribution of people with disabilities in planning, implementation and provision of services is reflected in their active participation in policy development, planning and their involvement on a range of committees” (Department of Human Services 2003)Pg 19

There is a focus on the creation, promotion and funding of community transport within rural South Australia, with the provision of an integrated transport service responsive to those most in need within the community. The education sector is responsible for access to education including

special needs transport. There appears to be no specific strategy for deal with the needs of Aboriginal people with a disability at a state policy and planning level.

The lead department on disabilities, Family and Community Services notes the importance of Aboriginal people in its 2004-07 Disability framework (Department for Families and Communities 2005). There are 29 references to the importance of Aboriginal disability services. However in the Family and Community Service Action plan the sole reference to Aboriginal issues is

“Aboriginal people and those from a non-English speaking background with disabilities have the right to have their unique needs met by the provision of services, which support access and equity and prevent discrimination on the basis of race and culture. )(Department for Families and Communities 2005) Page 9

There appears to be much work to be done to get Aboriginal issues on the mainstream disability agenda at state level.

At the local level, Port Augusta has developed a disability services strategic plan., Port Augusta has a significant Aboriginal population. The plan notes that

“Acquired brain injury and intellectual disability are reportedly the predominant disability types identified for the region. Of the 217 people identified with a disability, 27% have an acquired brain injury as their primary condition, followed by intellectual disability (26%), and physical disability (16%).

The majority of people with a disability identified within the region were reported as living with their family (70%), while others were reported as individuals living with others (19%), followed by those living alone (8%)” (Department for Families and Communities 2004) Page 6

The plan identifies transport as an important issue specifically noting the need to advocate for services for Aboriginal people living in the remote areas North of Port Augusta. The report concludes with the following:

“Transport services for people with mobility restrictions remain an issue in need of reform. Many funded agencies with large transport fleets use vehicles as a once-off trip, wait for passengers at the destination, often for several hours, before returning to their original location. In order to be financially viable and valued, a transport service needs greater flexibility of use and customer responsiveness.

State, Local and non-government agencies in both the disability and ageing sectors, acknowledge that uncoordinated transport services are costly and inefficient.” (Department for Families and Communities 2004) Pg 14)

The education sector in South Australia clearly identifies transport related issues.

“Aboriginal families deal with a number of agencies and attend numerous appointments and meetings when they have a child with a disability. They encounter problems of access related to information and/or transport. Understanding what is involved in obtaining assistance or managing to keep an appointment may provide challenges not understood by non-Aboriginal support agencies. It is necessary to build flexibility into service provision that recognises cultural differences. At the school level, it is important that consideration is given to assisting families with tasks such as filling in forms, keeping appointments or providing transport when required. These support requirements should be documented in the student’s Negotiated Education Plan.

A 'One-Stop Shop' involving collaboration between the health and education sectors, in both providing services and sharing information, would lessen some of the current problems with access. School sites could be used for screening and intervention services, as well as providing nutrition programs and other health related activities. The models currently being developed between the Nganampa Health Service and Anangu Education Services in Alice Springs, and the Healthy Ways Project involving the Department of Human Services and DECS, need to be extended and funding provided for this model to be applied in other regions of the State." ((de Bats 2003)pg 3)

The Ministerial Advisory Committee: Students with Disabilities. recommends

"Recommendation 7

Flexible service provision is critical for Aboriginal families. When Aboriginal students with disabilities are enrolled, schools should consider assisting with the completion of forms and attendance at appointments, including the provision of transport when required. This type of additional support must be included in the student's Negotiated Education Plan". (de Bats 2003) pg 5

Transport is a particular barrier for most Aboriginal families with a child with a disability but is even more troublesome for people who live beyond the metropolitan area.

"Transport is a major issue for many Aboriginal families. The ability of service providers to provide transport for appointments at short notice, or to undertake a home visit when that is required, will facilitate access to services for families whose lives are not always predictable. Current risk regulations that disallow travel in government cars, unless it has been pre-arranged a week or more in advance, has created a barrier for flexible service delivery." (de Bats 2003) Pg 46

"The particular problems of Aboriginal families with a child with a disability living in a country centre relate to the usual problems of distance and limited local support. Some of the services important for children with a disability are only available in the Adelaide metropolitan area (e.g. assessment for autism). It is necessary for a child and their family to travel to Adelaide in order to be diagnosed and receive services. While this is inconvenient for any family, it is particularly difficult for Aboriginal families with limited financial resources and lack of confidence with organisational requirements. Travelling to Adelaide involves leaving extended family and community connections, and people who understand the particular circumstances of the family." (de Bats 2003) Pg 46

There is a lack of consistency in the consideration of Aboriginal disability in South Australia. Poor data make it difficult to understand need. Aboriginal minority status makes it difficult to make claims for proper attention. The recent Evaluation of the National Disability Advocacy Program Final Report notes that while its main focus was not on Aboriginal people that

"Indigenous advocates felt that there is a fundamental lack of understanding about the nature of advocacy support required by Aboriginal and Torres Strait Islander people with disability. They considered that the advocacy required is not often short-term, as issues are complex and require ongoing and flexible approaches that do not always fit a traditional advocacy model. They maintain that it is common for an Aboriginal or Torres Strait Islander person with disability to require support for their whole life which will include all aspects of the individual's existence, such as housing, education, employment, access to adequate nutrition, access to transport, access to health services and any number of other important facets of a person's life. The extent to which such support is properly the role of an advocate or is a broader form of 'welfare' case management and service provision is clearly an issue. (Social Options Australia 2006) page 25

## 6.5 Discussion

### 6.5.1 Aboriginal disability needs: poorly defined and understood

There is a dearth of systematic literature on Aboriginal disability. Aboriginal disability policy and services operate in the shadow of mainstream services and ideas in a system which diversifies responses across a wide range of departments and agencies.

Aboriginal concepts of disability appear to be poorly understood by policy makers and service providers. There has been little research published on Aboriginal disability possibly due to the small numbers of Aboriginal people involved with medical disability has limited the study of this issue. However, while number are small in relative terms the prevalence is much greater and more complex than in non Aboriginal society. There is a great need to study Aboriginal disability in a systematic and culturally sensitive manner in order to determine what services are needed.

It is necessary to ensure access to the services and to acknowledge and support the Aboriginal community and in particular families of those with disabilities in meeting their cultural and family responsibilities.

The education sector through the Ministerial Advisory Committee: Students with Disabilities. 2003 has identified changes to services and the need for cooperation between sectors as vital to proper support of Aboriginal children with disabilities and their families. Their vision and clarity contrasts sharply with the lack of focus in many other sectors.

### 6.5.2 Transport and Aboriginal disability needs

The lack of good information about Aboriginal disability in general has an impact on the understanding of transport issues for Aboriginal people with a disability and their families. We could find no literature that systematically studies Aboriginal disability needs and issues of access and transport. One report 'Telling it like it is', describes responses from consultations with 400 disabled Aboriginal people and their carers across New South Wales. The point is made that while the historical focus on disability is that of a health perspective, that the social aspects of Aboriginal disabled people is lost in the shadows (Aboriginal Disability Network of New South Wales Incorporated 2007). Consideration of travel via public transport was lacking at infrastructure level:

“Participants in the consultations identified lack of transport as a major barrier to inclusion in ‘mainstream’ and their own community activities. For most communities, there was no public transport infrastructure, let alone accessible transport.” (Aboriginal Disability Network of New South Wales Incorporated 2007) p iv

Health focussed responses often provide only a partial solution to the whole of life situation of the person living with the disability, as the health sector has a narrow gaze that does not encompass all the aspects of the realities of individual differences and living situations:

“getting a wheelchair helps me around my home but it doesn’t help my whole life; I still can’t get down to the shops and go to places I want to go because the footpath is too bad.” (Aboriginal Disability Network of New South Wales Incorporated 2007) p2

In the course of the community consultation, some of the consequences of lack of access to public transport and lack of infrastructure were listed as:

- people confined to homes
- no access to employment, education, etc

- poor health outcomes (Aboriginal Disability Network of New South Wales Incorporated 2007)

Informal networks between communities was the key mode of access to services and communities for Aboriginal people (Aboriginal Disability Network of New South Wales Incorporated 2007). Due to the fluid nature of this type of network, it can be easy to understand that appointments would often be missed, and that regular commitments such as work or study would be hard to meet.

Issues of access to services are raised for all disabled people and it is clear that the population distribution and economic and social well being of Aboriginal people generates specific critical needs. These are described in more detail in the companion review on transport and Aboriginal health.

The lack of information should not however be used to delay action. The numbers of Aboriginal people with a disability are clearly underestimated due to lack of culturally appropriate systems to identify need. It is clear however that there are more than a thousand Aboriginal people with impairment or disability as defined by a health based definition and at least 10,000 who can be identified as being affected by broader social and educational disabilities.

While transport systems are only one barrier to access to services for assessment and support, they can be the focus of attention as other barriers are being addressed.

## 6.6 Responding to the needs identified

A person with a disability requires proper assessment and support. This can only be done if the services are easily accessible. Where a disability exists there are significant pressure on families and caregivers in meeting the direct load generated by the disability. There are multiple assessment meetings with a range of professions, meeting the different needs for daily living and adjusting to different education and support system. The prevalence of disability in Aboriginal communities is still largely unknown, with only New South Wales having undertaken extensive community consultation to examine the size of the problem (Aboriginal Disability Network of New South Wales Incorporated 2007). The 'Telling it like it is' report on the consultations recommends a national quantitative study be undertaken to establish the prevalence of Aboriginal people living with disabilities in the community, and that qualitative research to ensure community views and needs are voiced should be ongoing (Aboriginal Disability Network of New South Wales Incorporated 2007).

It is important that services are delivered in a manner that does not increase the costs to families by requiring a great deal of travel. Disability needs are less common than general health needs, so safe transport systems will either need to piggyback on the health system arrangements or will need to be especially arranged for individuals and their families.

It is likely that the improvement of transport access for all Aboriginal people will be needed to provide a foundation for improved access to disability services. The recommendation made for improvements to deal with health issues therefore apply to disability.

The issues identified in this paper need a cooperative multi-sector response and a level of cultural sensitivity not shown so far. Action is required at a number of levels:

- Core policy development that builds the communication strategies necessary for inter-sectoral cooperation,
- The transport needs of localities with high needs should be assessed and a coordinated response put in place. This response might include:



- improvement of road systems,
- use of shared community transport with accredited drivers in safe, well maintained vehicles to support patients and their families as they access health care and undertake cultural responsibilities such as attending funerals,
- Coordination of agency personnel's use of transport and freeing up of restriction on non employee travel in agency vehicles,
- Increasing driver training,
- Motor vehicle maintenance schemes and safety checks,
- Advocacy by Aboriginal agencies to ensure that needs are properly understood and that the policy options for the general population will not meet the needs of the younger and more highly stressed Aboriginal population, and
- Acceptance by government that in order to improve Aboriginal well being that the resources committed should be in line with the high level of need generated by poor health, cultural disruption and geographic distribution of health service.

In addition it is clear that transport that is appropriate to the needs of each disabled Aboriginal person is required. Transport needs of the person and their family needs to be a core part of assessment. It cannot be assumed that the generic response of policy makers and services to disabilities is adequate for Aboriginal people. Neither should it be assumed that passing responsibility to general Aboriginal agencies that have no specific expertise in disability will result in the necessary changes. There is a need to specifically address the transport needs of Aboriginal people with disabilities at core policy, departmental and local level. Failure to do so will mean that Aboriginal people to not receive the assessments or service they need and that they will be placed at risk trying to offset these deficits in ways that risk the safety of Aboriginal families and communities.

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