

CHAPTER 5 **ASSESSING THE NEED FOR SERVICES**

ABORIGINAL PERCEPTION OF DISABILITY: DEVELOPING A SHARED LEXICON

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Introduction

The Aboriginal Health Council of South Australia's two year study investigated the nature and extent of disability within South Australian Aboriginal communities. Participant observation and discourse with Indigenous people with disabilities, and their families and carers, helped identify service needs and preferences. Fourteen different communities were surveyed, ranging from individual family groups to extended families, community groups and Indigenous health teams, in towns and settlements such as Hawker, Port Augusta, Berri, Marree, Maitland, Mount Gambier, Coober Pedy, Ceduna and Yalata, as well as metropolitan Adelaide.

The study was initiated by the Aboriginal Health Council of South Australia (AHCSA) as part of their strategic planning process. Funding was provided by the South Australian Disability Services Office.

Research processes and critical issues

Critical issues associated with any research conducted in Aboriginal communities include:

- the initiation, ownership and control of culturally appropriate research processes; and
- the implementation of culturally empowering and functional outcomes for each community involved in the research process (National Aboriginal Health Strategy: An evaluation, 1994, Woenne-Green, 1995).

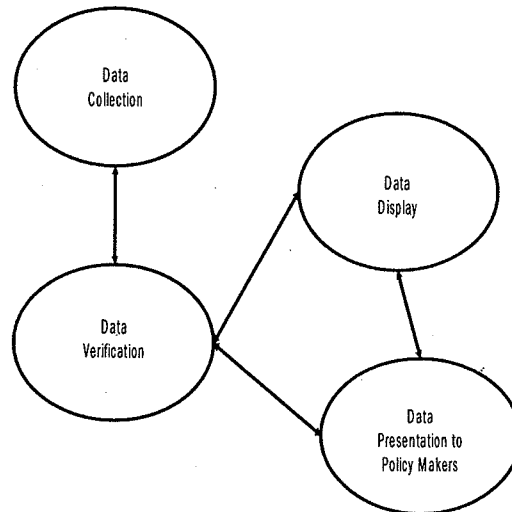
Central to the resolution of these research process issues is the nature and quality of the dialogue between Aboriginal communities, researchers, policy makers and service providers.

The experience of this study has generated awareness of the need for a pragmatic model of context for application in research processes. This pragmatic model involves a focus on understanding and affirming communication exchanges between researchers and members of Aboriginal communities. The model that has evolved seeks to provide cultural validity to quantitative and qualitative data gathered during the research process. The notion of achieving cultural validity involves a three-way process in which:

- Aboriginal views are presented to the researcher who includes cultural norms in data presentation;
- researchers check their interpretation of data with Aboriginal personnel; and
- jointly evaluated data is then presented to policy makers...who in turn identify with the 'agreed cultural norms' (Atkinson and Hammersley, 1994; Ellen, 1984).

The model of context developed for use in this research provides the basis for achieving cultural validity. Devoid of this model of context, any data concerned with the nature and extent of disability in the Aboriginal population, appears disconnected from the lives and communities of Aboriginal people. The model of context is pragmatic in the sense that it derives from social situations and returns inevitably to these situations.

1 Data processes for verifying cultural norms



The pragmatic view recognises that the most pertinent goal of this research should be that Aboriginal people can communicate effectively enough to affect the behaviour and responses of the researchers. This pragmatic model also emphasises the need for communication between Aboriginal people and researchers to be used efficiently across all environments. From a summative point of view, this also involves the researcher communicating data about Indigenous people as accurately and effectively as possible to policy makers.

The model has evolved from the writings of Lund and Duchan (1994) whose analysis of language and communication revealed the critical effect of context on the way in which language, and therefore information, is used and interpreted. The context of research has particular relevance for Indigenous peoples' willing expression of cultural norms and perceptions. For example, individual and community perceptions and experiences of disability and handicap are embedded within the cultural, social, economic, and political history of that community (Cohen, 1985; Ingstad & Whyte, 1995).

This model of context acknowledges the critical importance of history in understanding and interpreting impairment, disability and handicap within Aboriginal communities. In order to achieve a valid picture of data about disability in today's Aboriginal communities the model has to allow for the free flow of language used between Aboriginal people to convey their meaning about disability.

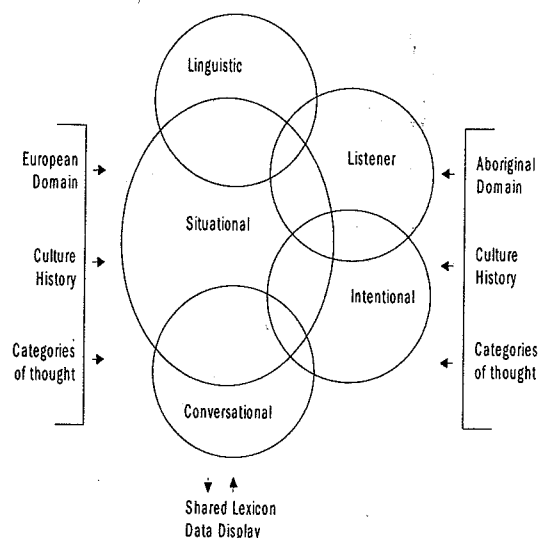
The model has five dimensions with associated sub-sets. These dimensions and sub-sets embrace the history, culture and value systems of Indigenous communities. The summary model in Table 1 includes the following contexts: situational; intentional; listener; conversational; and linguistic.

2 Research process model

1. SITUATIONAL CONTEXT Factors include:	This refers to the immediate setting in which observation, interview and survey takes place. Familiar places, people, objects and symbols, facilitate the free flow of conversation.
A. Physical location	People and objects that are present, and the activities that the people are engaged in.
B. The interaction	The participant's overall sense of what the interaction is about. It includes the routines, customs and behaviours associated with different types of interactions. Of particular importance is the language in which the interaction is taking place. Do both the speaker and researcher have a common language base?, are translators involved?, is one of the conversational participants using a second language?.
C. The topic	Refers to implicit and explicit strategies used in conversation about the particular topic.
2. INTENTIONAL CONTEXT Factors include:	This refers to the speaker's intention - what the speaker says and does to achieve a particular goal. It includes non-verbal, intonational and verbal acts.
A. Categories of intention Regulatory Informative Interactional Personal Heuristic Imaginative Instructive	Controlling Imparting knowledge Reciprocal exchanges Subjective Questioning Mental and visual imagery Teaching and guidance
B. Agenda	Agenda forms a second level of intentionality and refers to the individual agendas of both the speaker and listener. Different goals for the speaker and listener leads to conversation breakdown.
3. LISTENER CONTEXT Factors include:	Refers to the ability of the listener to enter the speaker's world. It also includes the listener's level of awareness of the relationship between him/herself and the speaker.
A. Role relationships	Reflects the power relationship between speakers and listeners. Language forms adopted by speakers are influenced by their perceived power relationship with the listener.
B. Cultural background C. Historical background - past and immediate D. Geographical and socio-economic background	The speaker's understanding and view of the world is shaped by the cultural, historical and socio-economic experiences of his/her community, and past and immediate family and individual circumstances. An awareness by the listener of the past and immediate lifestyle, priorities and values of the speaker, facilitates the generation of shared meaning in conversational exchanges.
4. CONVERSATIONAL CONTEXT	Refers to the extent to which a free flow of information (in the form of conversational exchange) takes place. It also refers to the rules, routines etc. that control turn-taking, commencing and terminating conversations, repairing breakdowns in meaning, who can and cannot participate etc.
5. LINGUISTIC CONTEXT	Refers to the understanding of the common linguistic devices, rules and behaviours used within conversation, that convey and control meaning. It represents the micro context of the interaction between the listener and speaker.

Figure 3 (overleaf) presents the model of context for research on Aboriginal perceptions and experience of disability in which contrasts are made between the separate foci and background of European Australians and Aboriginal persons.

3 Pragmatics of interaction research process



Conclusion

Any research process has to be sensitive to the needs and heritage of Indigenous communities. It has to be a process that is shared and accepted by both the researcher and Indigenous people. It is a process which allows for Indigenous ownership and identification with their data. This, after all, is the most researched community in Australia and one that sees few, if any, tangible results, following investigation. It is hoped that the three-way process of collecting, verifying interpretation, and presentation of data (Figure 1) will encourage policy makers to not only 'own' the results but also to take responsibility for effective implementation.

References

- Atkinson, P. & Hammersley, M. 1994, 'Ethnography and participant observation' in Denzin, N.K and Lincoln, Y.S (eds), *Handbook of qualitative research*, Sage Publications, London.
- Cohen, A.P 1985, *The symbolic construction of community*, Milton Keynes: The Open University.
- Ellen, R.F 1984, *Ethnographic research: a guide to general conduct*, Academic Press Ltd, New York.
- Ingstad, B. & Whyte, S.R 1995, *Disability and culture*, University of California Press, Berkeley and Los Angeles, California.
- Lund, N.J & Duchan, F.J (eds) 1994, *Assessing children's language in naturalistic settings* (2nd ed), Prentice Hall, New Jersey.
- National Aboriginal Health Strategy Evaluation Committee, December, 1994, *The National Aboriginal Health Strategy: An Evaluation* (ATSIC Commissioner, Stephen Gordon, Chairperson), Canberra.
- Woenne-Green, S. 1995, *They might have to drag me like a bullock. The Tjilpi Pampa Tjutaku Project*. The rights, needs and care options of the senior men and women of the Ngaanyatjarra, Pitjantjatjara and Yankunytjatja communities in the cross-border region of Central Australia, NPY Women's Council, Alice Springs.

THE TAREE STUDY - A MODEL FOR INDIGENOUS DISABILITY RESEARCH

By Neil Thomson, Associate Professor, School of Health Studies, Edith Cowan University

Introduction

It has been well known for many years that Australian Aborigines and Torres Strait Islanders are the least healthy identifiable sub-population in Australia, with levels of mortality and morbidity much higher than those of other Australians for almost all disease categories (Thomson 1991, Australian Institute of Health and Welfare 1996). Despite this, little effort has been made to assess the level of disability and handicap among Aboriginal and Torres Strait Islander peoples. Without such knowledge, it is not possible to develop appropriate programs and services for Indigenous people with disabilities, or even to ensure that those with disabilities are availing themselves of available programs and services.

The lack of information about indigenous disability and handicap led to the Taree study - an attempted census of disability and handicap among Indigenous people living in the Taree area of New South Wales. The study fieldwork was undertaken in 1991 by the Australian Institute of Health and Welfare (AIHW) and the Biripi Aboriginal Corporation Medical Service (based in Purfleet, via Taree).

In proposing the Taree study as a model for indigenous disability research, this paper summarises the methods and results of that study, full details of which are available in an AIHW report (Thomson & Snow, 1994).

The Taree study - methods

To enable the results of the study of the disabilities and handicaps of the Indigenous people living in the Taree area to be compared with information for the general Australian population, the approach used for the Taree study was adapted from that developed by the Australian Bureau of Statistics (ABS) for its 1988 Survey of Disabled and Aged Persons.

The Taree study followed the ABS's definitions of disability and handicap, which were based broadly on World Health Organization recommendations (WHO 1980).

A disabled person was defined as a person who had one, or more than one impairment or a disability which had lasted, or was likely to last, for six months or more

and

A handicapped person was defined ...as a disabled person aged 5 years or over who was further identified as being limited to some degree in his/her ability to perform certain tasks in relation to one or more of the following five areas: (a) self care; (b) mobility; (c) verbal communication; (d) schooling; (e) employment. (Australian Bureau of Statistics 1990).

Disabilities include both mental disorders (for example, mental retardation, slowness at learning and psychosis) and physical conditions (eg. loss of sight, incomplete use of limbs or digits and long-term conditions requiring treatment or medication). The ABS classifications of disabling conditions were supplemented by a number of specific conditions of particular relevance for Indigenous communities (eg. rheumatic heart disease).

There were two major differences between the Taree study and the ABS survey. First, the Taree study was confined to persons living in households, whereas the ABS survey also included persons living in health establishments and institutions. And, as noted above, the Taree study was an attempted census, while the ABS survey involved multi-stage Australia-wide sampling of the general population living in households and health establishments.

Both the Taree study and the ABS survey involved a two-stage collection of data. The first stage used a household screening questionnaire in which a responsible adult in each household was asked to provide simple demographic information about each person usually resident in that household and basic information about any disabling conditions of the residents. Based on information collected in this first stage, a second questionnaire was used to collect information about those individuals already identified as having one or more disabilities. This information was collected directly from the identified individuals, except where the person was aged less than 15 years, was unable to answer because of the nature of their disability, was temporarily unavailable, or experienced language problems. In these cases, information was obtained by proxy, usually from a responsible adult living in the same household.

As well as confirming that the person did in fact have one or more disabilities, the second stage obtained a range of other information about the primary disabling condition (the condition causing the most problems; also referred to as the most troubling condition) and whether the person was handicapped by their disability or disabilities. Children aged less than 5 years with a disability were assumed to be handicapped by their disability. As noted above, handicaps were assessed for five functional areas - personal care, mobility, verbal communication, education and employment. Except for children aged less than 5 years and people with an education or employment handicap, the severity of handicap was also assessed and classified as severe, moderate or mild (see Appendix on Pages 76-78).

In attempting a total coverage (or census) of all Indigenous people normally resident in the Taree area (which includes Taree, Purfleet, Forster-Tuncurry, Cabarita and surrounding areas), an initial list of Indigenous residents of the area was constructed from records maintained by the Biripi Aboriginal Corporation Medical Service. This list was supplemented by information obtained from the Taree City Council. As the study proceeded, information about other Indigenous residents of the area was sought from persons being interviewed. In this way, it is believed that virtually all Indigenous residents of the area were identified.

Another major difference between the ABS survey and the Taree study was the involvement of the Indigenous community. Much of the motivation for the study came from the Biripi Aboriginal Corporation Medical Service, which wanted information about the levels of disability and handicap among their client population, to enable the planning of services and programs.

The Service participated actively in the planning and conduct of the study, the ethics of which had been endorsed by the Service's Board of Directors and the AIHW's Ethics Committee. Participation in the study was, of course, also subject to individual approval, evidence of which was collected in the form of signed approval from each respondent. Most respondents also gave signed approval for access to their medical records for the purpose of clarifying uncertainties about their condition(s).

The Taree study - results

Population

Interviews were undertaken in 229 households, in which 999 people usually resided - 907 Indigenous people and 92 non-Indigenous people (Table 1). More than two-fifths of the households were in Taree town, with around a fifth in Purfleet and Cabarita.

1 Indigenous households and usual residents by location

Location	Number of households	Number of residents
Purfleet	46	242
Taree town	99	380
Cabarita	41	168
Forster/Tuncurry	16	46
Other	27	71
All locations	229	907

Source: Thomson & Snow, 1994

Of the 907 Indigenous people usually resident in the Taree area, 469 (51.7 per cent) were male and 438 (48.3 per cent) were female. Almost 44 per cent of males and almost 42 per cent of females were aged 14 years or less, and only 1.9 per cent of males and 2.5 per cent of females were aged 65 years or more. The mean age of males was 21.0 years, and the median 17.0 years. The mean age of females was 22.5 years and the median 19.0 years.

Prevalence of disability and handicap

Overall, 227 (25.0 per cent) of the 907 Indigenous people included in the study were identified as having one or more disabilities, 124 (13.7 per cent) as being handicapped by their disability and 46 (5.1 per cent) as having a severe handicap (Table 2).

2 Disability and handicap status of Indigenous usual residents of the Taree area by location

Location	With a disability.....		With a handicap.....		With a severe handicap (a).....		Indigenous residents
	no.	%	no.	%	no.	%	no.
Purfleet	53	21.9	28	11.6	9	3.7	242
Taree town	106	27.9	63	16.6	24	6.3	380
Cabarita	31	18.5	16	9.5	7	4.2	168
Forster/Tuncurry	13	28.3	6	13.0	1	2.2	46
Other	24	33.8	11	15.5	5	7.0	71
All locations	227	25.0	124	13.7	46	5.1	907

(a) Severity of handicap was not assessed for children aged less than 5 years.

Source: Thomson & Snow, 1994

Of the 469 Indigenous male usual residents of Taree, 117 (24.9 per cent) reported one or more disabilities, and 65 (13.9 per cent) of them reported being handicapped by their disability (Table 3). Of the 65 males with handicaps for whom severity of handicap was determined, 23 (4.9 per cent of usual residents) reported being severely handicapped. The prevalence of disability for Indigenous female usual residents was similar, with 110 (25.1 per cent) of 438 females reporting one or more disabilities (see Table 4, overleaf). The prevalence of handicap (14.8 per cent; 65 females reporting being handicapped) and severe handicap (5.3 per cent; 23 females) were slightly higher for females than males.

The prevalence of disability increases with age for Indigenous usual residents of the Taree area, as it does for the total Australian population. At all ages, the prevalence for Indigenous people exceeds that of the total population. For each population, the age-specific prevalence of disability is generally similar for males and females.

3 Disability and handicap status of Indigenous male usual residents of the Taree area by age group

Age group (years)	With a disability.....		With a handicap.....		With a severe handicap (a)....		Indigenous males no.
	no.	%	no.	%	no.	%	
0-4	8	12.1	8	12.1	n/a	n/a	66
5-9	20	26.3	10	13.2	7	9.2	76
10-14	12	18.8	5	7.8	1	1.6	64
15-19	12	20.7	8	13.8	3	5.2	58
20-24	8	20.0	3	7.5	2	5.0	40
25-29	3	9.1	1	3.0	0	0.0	33
30-34	11	28.2	6	15.4	2	5.1	39
35-39	10	33.3	3	10.0	3	10.0	30
40-44	6	28.6	4	19.0	3	14.3	21
45-49	4	50.0	4	50.0	1	12.5	8
50-54	4	66.7	3	50.0	0	0.0	6
55-59	9	90.0	6	60.0	0	0.0	10
60-64	3	33.3	1	11.1	0	0.0	9
65 or older	7	77.8	3	33.3	1	11.1	9
All ages	117	24.9	65	13.9	23	4.9	469

(a) Severity of handicap was not assessed for children aged less than 5. Source: Thomson & Snow, 1994

4 Disability and handicap status of Indigenous female usual residents of the Taree area by age group

Age group (years)	With a disability.....		With a handicap.....		With a severe handicap (a)...		Indigenous females no.
	no.	%	no.	%	no.	%	
0-4	6	8.6	6	8.6	n/a	n/a.	70
5-9	16	24.6	10	15.4	6	9.2	65
10-14	4	8.3	3	6.3	2	4.2	48
15-19	8	21.1	3	7.9	1	2.6	38
20-24	10	21.3	6	12.8	3	6.4	47
25-29	4	13.8	1	3.4	0	0.0	29
30-34	12	27.3	2	4.5	0	0.0	44
35-39	8	33.3	5	20.8	2	8.3	24
40-44	7	33.3	1	4.8	0	0.0	21
45-49	6	66.7	5	55.6	3	33.3	9
50-54	9	75.0	5	41.7	2	16.7	12
55-59	5	41.7	2	16.7	0	0.0	12
60-64	6	75.0	5	62.5	1	12.5	8
65 or older	9	81.8	5	45.5	3	27.3	11
All ages	110	25.1	59	13.5	23	5.3	438

(a) Severity of handicap was not assessed for children aged less than 5. Source: Thomson & Snow, 1994

Age-adjusted disability and handicap ratios

After adjustment for differences in the age structures of the Indigenous populations of the Taree area and the total Australian populations, the age-adjusted disability ratio for Indigenous males was 2.5 (95 per cent confidence intervals: 2.1-3.0), and the handicap ratio was 1.7 (1.4-2.1) (Table 5). For females, the age-adjusted disability ratio was 2.9 (2.4-3.5), and the handicap ratio was 1.8 (1.5-2.3). For severe handicaps, the age-adjusted ratio was 2.4 (1.5-3.6) for males and 2.3 (1.5-3.4) for females.

5 Age-adjusted disability and handicap ratios (a)(b) by sex

RATIO.....

	With a disability	With a handicap	With a severe handicap
Male	2.5 (2.1-3.0)	1.7 (1.4-2.1)	2.4 (1.5-3.6)
Female	2.9 (2.4-3.5)	1.8 (1.5-2.3)	2.3 (1.5-3.4)

(a) See Thomson & Snow, 1994 for age-adjusted disability and handicap ratios. (b) The 95 per cent confidence intervals are shown in parentheses. Source: Thomson & Snow, 1994

Disabling conditions

For males, the most frequent primary disabling condition was 'slow learning and specific delays in development', identified as the most troubling condition for 19 males (16.2 per cent of males with one or more disabilities) (Table 6). The next most frequently reported primary disabling conditions for males were 'hearing loss' (16 males, 13.7 per cent of males with one or more disabilities), 'asthma' (16, 13.7 per cent), 'heart disease' (7, 6.0 per cent) and 'arthritis and related conditions of the back' (7, 6.0 per cent).

For females, 'asthma' was both the most frequently reported primary disabling condition (17 females, 15.5 per cent of females with one or more disabilities), followed by 'hearing loss' (15, 13.6 per cent), 'unspecified mental, nervous or emotional conditions' (12, 10.9 per cent), 'slow learning and specific delays in development' (9, 8.2 per cent) and 'diabetes mellitus' (9, 8.2 per cent).

6 Most frequently reported disabling and primary disabling conditions (a) by sex

Sex by condition (a)	Any reported condition.....		Primary disabling condition.....	
	no.	%	no.	%
Males				
Slow learning/developmental delays	24	5.1	19	16.2
Hearing loss	22	4.7	16	13.7
Asthma	19	4.1	16	13.7
Heart disease	17	3.6	7	6.0
Speech impediment	11	2.3	4	3.4
Arthritis of the back	11	2.3	7	6.0
Musculo-skeletal deformities	10	2.1	5	4.3
Epilepsy	8	1.7	4	3.4
Females				
Asthma	26	5.9	17	15.5
Hearing loss	24	5.5	15	13.6
Unspecified mental/nervous/emotional	19	4.3	12	10.9
Heart disease	19	4.3	7	6.4
Slow learning/developmental delays	13	3.0	9	8.2
Diabetes mellitus	13	3.0	9	8.2
Hypertensive disease	11	2.5	7	6.4
Arthritis - other than back	11	2.5	6	5.5

(a) See Appendix for explanations of reported disabling and primary disabling conditions and for full wording of condition descriptions, which have been abbreviated in this table.

Source: Thomson & Snow, 1994

Handicaps

More than one-eighth of Aboriginal usual residents of the Taree area reported being handicapped by their disabilities, and about one in twenty were severely handicapped (see Table 2 on Page 70).

Overall, more people had a mobility handicap than any other type of handicap (Table 7). Of the 124 people identified as being handicapped by their disability, 87 (70 per cent) reported a mobility handicap. The next most frequently reported areas of handicap were employment (80 people, 65 per cent of people with a handicap) and education (74, 60 per cent). For males, the most frequently reported area of handicap was employment (44 males, 68 per cent of males with a handicap), and for females it was mobility (44 females, 75 per cent).

7 Area of handicap (a) by sex

Area of handicap	Males.....		Females.....		Persons.....	
	no.	%	no.	%	no.	%
Personal care	32	6.8	19	4.3	51	5.6
Mobility	43	9.2	44	10.0	87	9.6
Communication	11	2.3	8	1.8	19	2.1
Education	39	8.3	35	8.0	74	8.2
Employment	44	9.4	36	8.2	80	8.8

(a) See Appendix for explanations of areas of handicap. Source: Thomson & Snow, 1994

Summary

The levels of disability, handicap and severe handicap among Indigenous people living in the Taree area of New South Wales were much higher than those reported by the ABS for the total Australian population (ABS 1990), but methodological differences raise a number of issues about the comparability of the results:

- the Taree study was limited to people living in households, whereas the ABS survey also included people living in health establishments and institutions, for whom the prevalence of disability and handicap was much higher than for people living in households (ABS 1990). The number of people living in health establishments and institutions was small, however, so this difference results in only a slight underestimate of the age-adjusted disability and handicap ratios between Indigenous people and the total population
- the ABS survey was selected from the total Australian population using multi-stage sampling, while the Taree study attempted a census of the Indigenous population living in that area of New South Wales. One aspect affecting the comparability of results is the completeness of the attempted census. It is believed that only about 20 Indigenous households in the Taree area were not included in the study. If this estimate is correct, and there is no way of being certain, the overall response rate for households was around 92 per cent. Assuming that these households had the same number of residents per household as other Indigenous households in the area, but the same

prevalence of disability as the total Australian population, the prevalence for the estimated total Indigenous population of the area would be marginally lower than for people included in the study - 24.2 per cent compared with 25.0 per cent for disabilities, 13.6 per cent compared with 13.7 per cent for handicaps and 5.0 per cent compared with 5.1 per cent for severe handicaps.

The likely minimal effect of the methodological aspects suggests that the differences in levels of disability and handicap between the Indigenous population of the Taree area of New South Wales and the total Australian population are substantial. But, given the very heterogeneous nature of the Indigenous population of Australia, the applicability of the Taree results to other Indigenous populations is not clear.

A model for indigenous disability research

Given the very high levels of disability and handicap found among Indigenous people living in the Taree area of New South Wales, there is certainly a need to assess the levels of disability and handicap for Indigenous people living in other parts of Australia. As noted in the Introduction, it is not possible without this knowledge to develop appropriate programs and services for Indigenous people with disabilities, or even to ensure that those with disabilities are availing themselves of available programs and services.

An assessment of the levels of disability and handicap for Indigenous people living in other parts of Australia could involve an Australia-wide sample survey along the lines of the ABS survey. A better alternative would be the replication of attempted censuses - such as the Taree study - in a sample of Indigenous communities (including a variety of community types). A series of such censuses would be much more manageable than an Australia-wide survey.

This approach also has the very distinct advantages of being undertaken in partnership with Indigenous communities (rather than being largely imposed from outside) and of being able to contribute directly to the health planning for these communities. Certainly the experience of the Taree study - undertaken in partnership with the Biripi Aboriginal Corporation Medical Service - was very successful, and suggests that such partnerships should work well throughout Australia.

References

Australian Bureau of Statistics 1990, *Disability and handicap, Australia 1988*, ABS Catalogue No. 4120.0, Canberra, Australian Bureau of Statistics.

Australian Institute of Health and Welfare 1996, *Australia's health 1996: the fifth biennial report of the Australian Institute of Health and Welfare*, Canberra, ACT, Australian Government Publishing Service.

Thomson, N. 1991, A review of Aboriginal health status, In: J. Reid & P. Trompf (eds). *The health of Aboriginal Australia*. Sydney, NSW, Harcourt Brace Jovanovich.

Thomson, N., & Snow, C. 1994, *Disability and handicap among Aborigines of the Taree area of New South Wales*, Australian Institute of Health and Welfare: Aboriginal and Torres Strait Islander Health Series, No 9, Canberra, AGPS.

World Health Organization 1980, *International classification of impairments, disabilities and handicaps: a manual of classification relating to the consequences of disease*, Geneva, World Health Organization.

APPENDIX

Aids

An aid was defined as a device or appliance used by a person with a disability to help with the performance of every day tasks. Aids include such devices as dressing hooks, special cutlery for eating, appliances to assist with washing and toileting (including rails, straps, etc.), artificial limbs, wheelchairs, walking sticks, and hearing, speaking and writing aids. In this study, help of a personal or organisational nature was not considered to be an aid.

Area of handicap

For people with one or more disabilities, assessment was made of the degree to which their disability handicapped them in the performance of tasks in five functional areas:

- *personal care* - difficulties in showering, bathing, using the toilet, dressing and/or eating
- *mobility* - difficulties moving around the home, moving around outside the home, walking 200 metres, walking up and down stairs and/or in using public transport
- *verbal communication* - difficulties understanding or being understood by strangers, family, and/or friends in the person's native language
- *education* - person was unable to attend school, attended a special school, attended special classes in an ordinary school, needed time off from school and/or had difficulty at school because of disabling conditions (information collected only for people aged 5 to 14 years and those aged 15 to 20 years still attending school)
- *employment* - person permanently unable to work, restricted in type of work they could do, often needed time off work, restricted in number of hours they could work, would require an employer to make special arrangements, and/or limited in prospects of obtaining, keeping and/or changing jobs (information collected for people aged 21 to 64 years and those aged 15 to 20 years not attending school)

Assistance

A person with one or more disabilities was assessed as needing assistance if they needed assistance or supervision to do one or more specified tasks or, in some cases, would find the task(s) difficult to do alone. Assistance did not include the use of aids or appliances.

An assessment was made of the person's need for assistance, regardless of whether or not it was actually received. For those people receiving assistance, the source of the assistance could be individuals or organisations, and it could be formal or informal.

Conditions

Conditions were broadly grouped under Mental disorders, Physical conditions and Other disorders and conditions as follows:

Mental disorders

Mental disorders other than retardation, degeneration or slow at learning

Senile psychoses

Other psychoses

Unspecified mental, nervous or emotional condition

Mental retardation, mental degeneration due to brain damage, slow learning and specific delays in development

Mental retardation

Mental degeneration due to brain damage

Slow learning and specific delays in development

Physical conditions

Disorders of the sense organs

Eye disorders - sight loss

Eye disorders - no sight loss

Ear disorders - hearing loss

Ear disorders - no hearing loss

Nervous system disorders

Paralysis

Epilepsy

Migraine

Speech impediment

Other disorders

Circulatory system disorders

Hypertensive disease

Heart disease

Rheumatic heart disease

Other disorders

Respiratory system disorders

Asthma

Chronic airways disease (including bronchitis and emphysema)

Other respiratory disorders

Disorders of the musculoskeletal system and connective tissues

Arthritis and related disorders of the back

Arthritis and related disorders, other than the back

Absence of limbs or parts of limbs

Musculoskeletal deformities (excluding absence of limbs or parts of limbs)

Other disorders

Other disorders and conditions

Neoplasms

Diabetes mellitus

Other endocrine disorders

Ulcer - stomach/duodenum

Other digestive disorders

Abdominal hernia

Skin and subcutaneous tissue disorders

Alcohol dependence

Urinary tract disorders

Other disorders

Disability

Based broadly on World Health Organization recommendations (WHO 1980), the ABS defined a disabled person as someone who had one or more disabilities or impairments which had lasted or was likely to last 6 months or more.

Disabilities may result from both mental disorders and physical conditions. The Taree study followed ABS's broad groupings of mental disorders and physical conditions, but also included a number of specific conditions of particular relevance for Aboriginal communities (for example, rheumatic heart disease).

Handicap

A handicapped person was defined as someone whose disability limited their capacity to perform tasks in one or more functional areas (ABS 1990).

Primary disabling condition

The primary disabling condition was defined as the condition identified by a person with more than one disability as causing the most problems. For a person with only one disabling condition, that condition was his/her primary disabling condition.

Severity of handicap

For people with a handicap aged 5 years and older, severity of handicap was assessed for handicaps in the areas of personal care, mobility and verbal communication (severity of handicap was not assessed for people with only an education or employment handicap). The assessment was based on the person's ability to perform tasks in the areas of personal care, mobility and verbal communication and on the amount and type of assistance required. The severity of handicap for each person was defined as the highest level of severity in any of the three areas. Severity of handicap was classified as:

- *severe* - personal assistance or supervision required and/or the person was unable to perform one or more of the tasks
- *moderate* - no personal assistance or supervision required, but the person had difficulty in performing one or more of the tasks
- *mild* - no personal assistance or supervision required and the person had no difficulty in performing any of the tasks, but used an aid, and/or had difficulty walking 200 metres and/or up and down stairs.

References

Australian Bureau of Statistics 1990, *Disability and handicap, Australia 1988*, Catalogue No. 4120.0, Australian Bureau of Statistics, Canberra

World Health Organization 1980, *International classification of impairments, disabilities and handicaps: a manual of classification relating to the consequences of disease*, World Health Organization, Geneva

DO/ HOW DO/ SHOULD DEFINITIONS OF DISABILITY INCORPORATE INDIGENOUS PERCEPTIONS OF DISABILITY?

By Louis Ariotti, Lecturer, Indigenous Higher Education Unit, University of Southern Queensland

The topic of my talk this afternoon 'Do/ how do/ should definitions of disability incorporate Indigenous perceptions of disability?' doesn't necessarily indicate an indecisive and fuzzy mind. It shows the difficulty of having to come up with a title for a talk on the spur of the moment. On reflection however, the three elements can throw some light on our deliberations over the next two days.

Firstly, should Indigenous perceptions of disability be incorporated into definitions of disability?

At the risk of oversimplifying, the answer seems strongly in the affirmative, especially as the context is a cross-cultural one. Gregory (1994) said about another indigenous group - the Maori people:

The loss of spiritual values accompanying deculturalisation, the subjugation of Maori people to Pakeha people historically, and the loss of land, language, health, roles, jobs, and so on represent a form of disability. Physical or sensory disability, as written in the Western sense, is but an added and rather minor aspect of a much larger issue. To neglect the importance of this is to miss the value of cross cultural comparisons (p195).

In the production of high quality data, we need to have a good insight into how each cultural group perceives and understands disability and related terms. We need to take seriously, the heterogeneity of Aboriginal groups.

The second part of the question - how do definitions of disability incorporate Indigenous perceptions? will be the bulk of my talk this afternoon. I will do this by describing a study I undertook amongst the Anangu in the cross-border regions of South Australia, Northern Territory and Western Australia.

Background

The study was undertaken in 10 communities over a 12 month period in 1994/5. The history of Anangu contact with Piranpa (white fellas) is only relatively short. A mission was established in Warburton in the mid 1920s and Ernabella (in the east) in 1937.

I worked for four years as a community health nurse in this area, but in order to collect data for the project, I needed a job that gave me greater freedom to move all around the cross border region. This opportunity came via a position with the Commonwealth Rehabilitation Service (CRS). They were in the process of establishing a pilot project to examine the feasibility of providing tertiary rehabilitation programs in the isolated communities in the cross-border region. The CRS position proved very important for two reasons:

- it allowed me to work closely with the Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women's Council which, 12 months before, had established the Disability Support Project (DSP) in the same region; and
- I was able to travel throughout the cross border region not simply doing research, but in a position where I was able to provide a number of immediate services to people with disabilities.

A grant from RHSET allowed me to employ an Anangu woman from Ernabella as a co-worker. She was invaluable to the project.

The main sources of data were:

- interviews with 53 people, and/or a family member, who presented, or were referred to CRS;
- six people who volunteered to give a lengthier and more in-depth interview; and
- a transcript of a two day work shop on disability issues initiated by the DSP steering committee and attended by 80 Anangu. This was called the Uwankaraku Meeting, a name decided on by the steering committee precisely because of the problem of defining disability. Uwankaraku means 'with everyone', those with a disability and those without.

Results

The data, which were more exploratory than definitive, fell into three categories:

- an exploration of the experience of disability;
- an exploration of the meaning of disability; and
- an exploration of the needs of people with disabilities.

Because of time constraints, I wish this afternoon to concentrate only on the first of these, the experience of living with an impairment or disability in a remote Aboriginal community.

The experience

As would be expected, there was a range of conditions that resulted in some degree of impairment or disability amongst the 53 people. These were:

- diabetes: with impairments ranging from lethargy to progressive amputation;
- respiratory disease: some mild as in asthma to extensive disease causing the death of a 19 year old two months into the project;
- Rheumatic heart disease;
- four people with impairments post poliomyelitis;
- five people with amputations;
- hearing impairment; and
- the most tragic group - seven men with varying degrees of organic brain injury as a result of petrol sniffing.

Each person's experience of their impairment or disability is, of course, unique.

However, in an attempt to explain the experience in more general terms, five categories were developed, based on the experiences related to me by the participants.

Group 1: People with severe disability

Anangu refer to these people as the *ngultutjara mulapa* - really poor things (is the literal translation) the most disadvantaged (is the freer translation).

There are two sub-groups. The first sub-group is comprised of those in foster homes and supported accommodation in one of the major towns; Perth, Adelaide or Alice Springs.

The main issue with this group is the fact that the family has little control over, or say in the care of, these people.

As one grandmother said at the Uwankaraku Meeting:

I got a grandson in Alice Springs. This is my sister's daughter's grandson. He never comes and visits the families and he's away from the families. I want to ask the question why we couldn't go and see the little boy in Alice Springs.
(Grandmother)

The second sub-group are those with an obvious and serious impairment, who are living in the community.

An example is a 17 year old boy with a below knee amputation. This, you may think, does not sound like a severe disability. But the fact that he has not let anyone look at his stump for four years, and the fact that he spends most of the time lying on a mattress, leads many Anangu to class him as *ngultutjara mulapa*.

Group 2: Persons with an impairment who do not consider themselves, and are not considered by others, to have a disability

This stems from the fact, that to a large extent, people still participate in various aspects of community life and do many of the things that they want to do.

One such person was a 25 year old man with dwarfism. He drives a large front end loader and can only do so by standing up to work the controls. He is also an accomplished graphic artist on the computer. He does not consider himself to be impaired or disabled.

Another example is an old woman with a long standing neuropathy of the legs. People call her *tjirara wiya* - the one with no legs. She sits for hours in her camp making artefacts. She often goes hunting by being unceremoniously lifted into the back of a Toyota. When CRS and the DSP offered to provide her with aids to assist her mobility and lessen the hardship, she refused them - all she wanted was hot water in her shower.

Group 3: Persons with an obvious impairment who accept they have a disability, but do not group themselves, and are not grouped by others, with person's having disabilities.

This group is different to the previous one in that they do accept that they have a functional loss or limitation, that is, a disability. This group accepts aids; the previous group did not. They are different from Group 1 because their disability is not as severe and they do not accept the description of *ngultutjara mulapa*. Importantly, their disability is a personal thing. They know they are different to other people, but in the same way that someone with a big nose or big ears is different.

Group 4: Persons encouraged to adopt the role of a person with a disability.

Three of the 53 participants fit this group. The parents of three participants said that their sons, whose ages were 19, 23 and 30, had a 'disability', but there was some question about the presence of, or degree of, impairment.

For example, the parents of the young man with rheumatic heart disease asked to speak to CRS. They said he is sick and 'feels weak'. They wished him to receive the Disability pension. I spoke to the community doctor who said that he had been asymptomatic for a couple of years and had, in fact, played football within the last 12 months. We might be tempted to think it was just a ploy to get the pension. It may have been, but it was not typical.

The father of the 30 year old man initially told me that his son had 'a sore knee' and would we talk to him. We did a couple of days later. He said he hurt his knee 10 years before. He had not seen the doctor in all that time. It only caused him any inconvenience when he ran. The fact that he couldn't play football was his main problem. He and his father wanted to know if there was anything CRS could do. No mention of the pension was made.

A number of possibilities arise from this group:

- the people misunderstood the way CRS was using the term disability;
- they used CRS as a way of obtaining more funds;
- previously the men had been sick or injured and the 'disability' resulting from the acute phase of their impairment continued even after the 'impairment' disappeared.

Group 5: Persons with minor impairments but, in their estimation, a significant disability.

Most of the 53 people who approached CRS fitted into this category. They have a disability or limitation on their activities resulting from an impairment, and they want *someone* or *something* to help alleviate the hardships they experience. The people believe that the main role of the DSP and CRS is to give things to people with something wrong with them.

A 33 year old woman, for example, had fingers missing from one hand as the result of a burn accident as a child. As a teacher she wanted to teach the children how to count by using her fingers. She felt that this was not possible because she was shamed when she put her hand with the missing fingers in the air. She wanted CRS to help with a prosthesis that would cover up her missing fingers and allow her to use her hand to count.

These five groups represent the individual's experience of impairment or disability. There is another equally important dimension to the understanding Anangu have about disability, and that is the social experience and perspective.

Social perspective

This social perspective of disability is manifested most clearly in the loss of control people have over their lives. Neither the person with the disability, nor their family, has much say about where, or with whom the people with disability can live. The perception

is that departmental officers (Welfare) assume this responsibility with little or no consultation with the person or the family.

Over thirty years ago, Putja was three when she was sent to Adelaide for treatment and rehabilitation as a result of poliomyelitis. That, in itself, is understandable. What she cannot understand to this day, is why, when her time in hospital was finished, she was put in the care of a European family in Adelaide, without any consultation with her family. The family discovered her whereabouts when a friend who lived in Adelaide, sent them a photograph cut from a newspaper. Putja's perception was that the father of a white boy in the bed next to her simply wanted to look after her and there was no consultation with her natural family.

I said to her: 'Tell me about the photo in the newspaper. Did your father know where you were?'

Putja: 'They didn't know where I was. Only when Bud [family friend living in Adelaide] told my father. They saw the photo and knew I was in Adelaide. Then my father came down and visited me. I was only a little child then. About five or six and I had a little teddy bear.'

This sort of perception continues today. The Anangu feel that their children with severe disabilities continue to be removed from the influence of their family, community and culture without parental permission. This was one of the main impetuses for the Uwankaraku Meeting. At an organising meeting, one of the women said:

It used to happen in the past that kids were taken off parents because of their disability and the parents thought it would be for a short time but it ended up that they did not come home. The kids only heard English being spoken and therefore it was hard for them to come home if they ever had the opportunity. It was sometimes hard to get the kids off their foster parents. Some rules need to be put on paper to ensure that this does not happen any more.

For Anangu the loss of culture and identity is perhaps the most important feature of disability. The importance of this was highlighted on a number of occasions.

The father of one child said:

Welfare sometimes keeps disabled or crippled children at Alice Springs or Adelaide ... If a white fella takes these children and looks after them in Adelaide or Alice Springs they can't learn my culture or Law, the Dreaming places of our grandparents.

and a grandfather lamented:

Welfare put her in a foster family. White fellas' society. But today [Uwankaraku Meeting] is the chance to talk to welfare and say that I don't want the kids to be treated in whitefella way. I want the kids treated in the way I want the culture and law and all these other things. (Grandfather)

Whilst exploring the needs of people with disabilities, I discovered that the most fundamental need expressed was their desire to be in control. This was succinctly stated on a number of occasions. They said 'We want to be responsible for our own children', and 'We want to keep the old and disabled at home in the community'.

The impairment phase

To understand how Anangu are in the process of defining disability, we need to keep in mind that prior to the coming of the Piranpa, which if you recall was not all that long ago, the Anangu did not have the language to express the concept of disability. People had impairments and they were generally accepted as part of the normal composition of the community, 'normal in the sense that they are part of the accepted diversity of humanity, involving the acknowledgement and acceptance of difference' as Branson and Miller put it (1992, p18).

The oppressive phase

In addition, Fulcher (1989) poignantly stated:

How people with power respond to what *they* perceive as disability constructs the nature of disability (p43).

Anangu have been introduced to a concept of disability that has been defined by the medical and welfare professionals, the bureaucrats and the politicians. Historically, it is the professionals who see disability only in terms of disease, trauma and physiological disorder. It is the powerful 'helping' professionals who declare if a child is (severely) disabled and must be taken away from the family and community and culture. If this 'new' word 'disability' means anything to Anangu, it means that children will be taken away and they will lose all contact with the roots of their religion and culture.

Conclusion

What this project has taught me, and what I think we can take from this brief account of that project, is that people increase their sense of control over what is happening to them when they define their own experiences and situations in their own terms (H.A.L.T. 1991). This was why I titled my thesis 'A newly planted tree'. The Anangu have begun the process of empowering themselves. Hopefully, deliberations like ours over the these two days will assist them in that process and not hinder them.

References

- Branson, J & Miller, D. 1992, 'Normalisation, community care and the politics of difference', *Australian Disability Review*, 4, pp 17-28.
- Fulcher, G. 1989, 'Disability: a social construction', in G.M. Lupton & J.M. Najman (eds), *Sociology of Health and Illness*, University of Queensland Press, Brisbane.
- Gregory, R.J. 1994, 'Disability and rehabilitation in cross-cultural perspective: a view from New Zealand', *International Journal of Rehabilitation Research*, 17, pp 189-200.
- Healthy Aboriginal Life Team [H.A.L.T.] 1991, *Anangu Way*, Nganampa Health Council Inc., Alice Springs.

PLANS FOR TESTING THE BETA ICIDH- 2 IN THE AREA OF INDIGENOUS AUSTRALIANS WITH A DISABILITY

By Kate Senior, The North Australia Research Unit, Australian National University

Introduction

Indigenous people have been found to have high levels of both physical and mental disabilities. The National Aboriginal and Torres Strait Islander Survey (1994) found that an estimated 3% of Indigenous people over 5 years old had a severe or profound handicap. In the 45-54 age category, an estimated 8% of Indigenous people had a severe or profound handicap, compared to 4% of the general population (ABS 1997). Studies of disability in Indigenous communities in the south-east of Australia have found that levels of disability are considerably higher than in the non-Indigenous population. In a survey of the Taree area, Thomson and Snow (1994) found that levels of disability were 2.5 times higher for males and 2.9 times higher for females, when compared with the Australian Bureau of Statistics results for the Australian population. Similarly, Henderson and Gray (1994) found, in a survey conducted in western Sydney, that there were higher levels of disability in all categories of physical functioning when Aboriginal people were compared to non-Aboriginals.

While there have been efforts to quantify the number and types of disabilities, there have been few studies into the perception and experience of being an Aboriginal person with a disability. Those studies which have been done are difficult to replicate and use for comparative purposes, due to a lack of consistency of definitions of impairment, disability and handicap (or impairment, activities and participation in the new ICIDH). This paper will review the current studies of Aboriginal perceptions of disability, and discuss plans to test the relevance of the International Classification of Impairments, Activities and Participation (ICIDH-2) in a remote Aboriginal community.

Problems with obtaining information on Aboriginal disability

Gething (1994) emphasises that it has been very difficult to collect information about Aboriginal disability due to cultural differences in perceptions of Aboriginals and non-Aboriginals. It may be, for example, that some conditions are so common and expected in a community that they are considered to be normal, and are therefore unlikely to be mentioned, as the following quotation illustrates:

At Yirrkala, recurrent upper respiratory tract infections and habitual smoking of pipes and cigarettes commonly cause a loose productive cough. Such coughs alarm non-Aborigines, but they do not unduly worry Yolgnu.
(Reid, 1983)

It may be that some conditions are ascribed more importance than others. Research into lower back pain in a central Australian Aboriginal community, found that while lower back pain was a common occurrence, it was rarely acknowledged. In contrast, a headache and neck pain caused a great deal of distress. The reason being that the above symptoms were indicative of the person having committed a major social transgression. Headaches and neck pains were therefore a greater cause of fear than lower back aches (Honeyman & Jacobs, 1995). This highlights how the issue of causality may change how an individual responds to a health condition.

It may also be difficult for an outsider to recognise people with disabilities in remote communities, because the context in which disabilities are usually recognised is so different. For example, unemployment and limited schooling may be the norm and

intellectual disabilities and hearing and sight impairments may be hidden. Furthermore, an individual may receive a great deal of assistance in their everyday life from their family and friends.

Bostock (1991) and Gething (1994) also argue that the disability itself may be considered to be secondary to issues which are perceived as having a greater importance:

...issues associated with social stigma and disadvantage from being Aboriginal are more important than disability. (Gething, 1994)

Ethnographic accounts of disability

Aboriginal beliefs about the causation and treatment of illness have been extensively examined, for example: (Reid, 1983, Taylor, 1977, Wiminydji & Peile, 1978). The studies show that concepts of health were intertwined with ideas of maintaining social harmony, conforming to social and spiritual norms of behaviour, and a person's connections with traditional lands. As mentioned above, the perceived cause of a person's disability could very well have an effect on their experience of the disability (Elliot, 1994, Ariotti, 1997). The information specifically on the experience of people with disabilities is more limited. A number of accounts demonstrate the tolerance and great efforts taken to ensure the continued participation of those with disabilities, in the life of the group, (Berndt & Berndt, 1964) and this example from Kalberry (1939):

One woman of Forrest River carried her mother, who was blind and old, part of the way on journey to her horde country.

There are however, accounts of old and frail people being left behind:

They had just left Wongan Hills when old Wunu came to a standstill. He couldn't go another step. 'Leave me here', he said to the rest. 'I will die here'. He knew the procedure. When a member of the tribe was too old or sick and became a handicap, the only thing to do was to leave that one to die. It was harsh reality in nomadic life of subsistence. So they did what he asked. They made a big fire with plenty of wood beside him, and left him in the bush. They never saw him again. (Morgan, 1986, cited in Ariotti, 1997:49)

Several authors also comment that new-borns with significant physical disabilities were killed at birth (Meggitt, 1964; Cowlshaw, 1979). Western medicine and the change to a sedentary lifestyle has made accommodation of people with disabilities possible (Elliot, 1994). For these reasons, Zierch (1990) comments that the integration of people with serious disabilities into remote Aboriginal communities is a recent phenomenon.

Aboriginal perceptions of disability

Recent studies of Aboriginal perceptions of disability are very limited. In a study undertaken for the Commonwealth Rehabilitation Service, Elliot (1994) makes the following points about social perceptions of disability in remote Aboriginal communities:

- social stigma is not attached to disability;
- an impairment was only of concern to a person if it lead to handicap, people identified as having a handicap were those who needed assistance with the activities of daily life; and
- elderly people were not regarded as being disabled, their limitations were considered to be a normal part of ageing.

A Department of Health, Housing and Community services needs assessment report on people with handicaps, and the frail aged, in five Aboriginal communities in the Northern Territory, (1992) found that the word handicap was disliked. In addition, there was significant social stigma associated with being labelled as 'handicapped'. Because of this, the term was only thought to be applicable to a very small group of people.

The only individuals routinely agreed to be 'handicapped' are children with severe disabilities residing in institutions in Darwin. And even in these cases the families of such children do not approve of the term.

Ariotti's (1997) study of the Anangu perception of disability found that some people, and especially those with obvious physical impairments, such as amputations, were ashamed and embarrassed about their appearance, to the point of avoiding other people. He also found that there were a number of people who seemed to have minor impairments, but who regarded these as constituting a major barrier to their participation in the community. For example:

Ngau, for example, has fingers missing from one hand. She is a teacher and wants to use her fingers to demonstrate to the children how to count. She feels that this is not possible because she is shamed when she puts her hand with the missing fingers in the air (Ariotti, 1997:115).

Ariotti also found that a person's perception of their own disability was also dependent on the knowledge of available aids and services. He described the case of one elderly woman who was unable to walk, but did not consider herself to have a disability, because she considered that she was able to do most things she wanted to do (talk to friends and family, make artefacts). When she visited another community and saw a person using a motorised wheelchair she was suddenly made aware of increased opportunities for participation in her own community.

The definitions of impairment, disability and handicap used in the literature

While the available research on Aboriginal perceptions of disability has been very informative, a fundamental problem remains with the lack of consistency of definitions and the fact that the concepts of disability and handicap are often used interchangeably. The ICIDH-2 provides the following definitions, with the words disability and handicap being replaced by what are considered to be 'neutral terms'; activity and participation.

1 ICIDH definitions

In the context of a health condition:

Impairment	A loss or abnormality of body structure or of a physiological or psychological function.
Activity	The nature and extent of functioning at the level of the person. Activities may be limited in nature, duration and quality.
Participation	The nature and extent of a person's involvement in life situations in relationship to Impairments, Activities, health conditions and Contextual factors. Participation may be restricted in nature, duration and quality.
Context	Includes the feature, aspects, attributes of, or objects, structure, human-made organisations, service provision, and agencies in the physical, social and attitudinal environment in which people live and conduct their lives.

The ICIDH-2 recognises that there does not need to be a linear progression from impairment, through activity to participation. For example, someone who has been diagnosed with HIV may not experience any changes in functioning, but less than full participation in society may result from discrimination due to the disease.

Elliot's (1994) report does not define either disability or handicap, but instead uses the following examples to show how the concepts are not used interchangeably.

Cases	Disability	Handicap
1. Illness/trauma (car accident paraplegic)	loss of mobility	unable to perform basic functions for self (eg. wash)
2. Illness/trauma (eye disease)	loss of vision in one eye	no handicap, unless other eye blinded

According to the ICDH-2 definitions, however, the examples for Case 1 are both restrictions of activities (old disability definition). Participation (old handicap definition) in cleanliness is about the quality of a person's cleanliness, and their satisfaction with their cleanliness, given contextual factors such as 'availability of water and cleaning media, the presence and usefulness of bathrooms' (ICDH-2, 1997).

In Case 2, a participation restriction would occur if the person with vision in only one eye was prevented from participating in an activity such as schooling, playing sport or driving, due to their inability to see. Or if they were perceived by other people to be incapable of participating in such activities.

The Department of Health, Housing and Community Services report (1992), provided the following definition of handicap:

Handicap is any compromise in the ability of an individual with a disability to independently maintain the basic survival roles (orientation, personal care, mobility, social integration, or economic viability) because of that disability.

In the ICDH the classification of participation covers more than a basic survival role and extends to 'those areas of human life in which people experience restrictions in the quality, character or degree of participation normally expected of people without disablements'.

Ariotti, (1997) in agreement with Gething and Bostock, considers that Aboriginal people are fundamentally handicapped by a legacy of colonisation and dispossession and the attitudes of society towards Aboriginal people. Therefore, he considers that such factors as petrol sniffing and poverty, are pre-existing handicaps which may have a particular effect on a person who has a disability. The definitions Ariotti provides are therefore broadened to include such factors.

2 Modified ICDH definitions

Impairment	The loss or abnormality of psychological, physiological or anatomical structure or function. The loss may result from a birth defect, medical condition, social and political factors, or the intervention of a supernatural being or power.
Disability	The long-term permanent functional loss or limitation experienced by an individual as a result of a) their impairment and/or b) the contemporary social organisation which takes little or no account of people with impairments.
Handicap	The social consequence caused by environmental or social conditions which prevent a person, group or community from achieving the maximum potential or participation they seek. It refers to architectural, attitudinal, educational, occupational, legal, political and personal barriers to independence. (Ariotti, 1997: 45)

The ICDH, however, does not see restrictions caused by a person's gender, race, social class, economic condition or religion as being relevant (ICDH-2, 1997:179).

Furthermore, activities such as petrol sniffing would not be seen as a restriction of participation, rather, the petrol sniffing may be the cause of some impairment which prevents full participation.

ICIDH and the measurement of quality of life

I am interested in examining the concept of quality of life in remote Aboriginal communities, with the aim of developing, or making recommendations regarding the development of, a culturally appropriate quality of life instrument. There has been much debate in the literature as to what aspects of human life 'quality of life' encompasses and there has also been confusion between measurement of health status and quality of life.

For example, it is argued that the SF-36, which is described as a quality of life measure, is actually a measure of health status, as it asks people what they can and can't do as a result of their condition and not how they *feel* as a result of these limitations (Ruta, 1997). Therefore, the SF-36 relates to the activities dimension of the ICIDH as shown in Table 1 (Page 87).

Actual quality of life is considered to be a phenomenon which is entirely individual. Each individual will regard different things as being important to their quality of life. It has therefore been argued that a quality of life instrument with set questions will fail to be relevant, as it may not capture the areas of life which are considered to be most important to the individual (Ruta et al, 1994; O'Boyle et al, 1992; Hickey et al, 1996). In order to create a valid quality of life instrument, several researchers have developed measures, such as the Patient Generated Index (PGI) and the Schedule for the Evaluation of Individual Quality of Life (SEIQOL), which require the patient to nominate their own most important life areas.

The relationship between quality of life and the participation dimension of the ICIDH is clear as both rely on subjective judgements on what activities an individual wants to participate in, and if they feel fulfilled in the extent of their participation.

	ICIDH	Type of measurement	Examples
	Impairment	clinical measurements Objective	glycosylated haemoglobin in diabetes
Health Status	Activity (Disability)	What a person can and can't do as a result of the impairment Objective or subjective	SF-36
Quality of life	Participation (Handicap)	How the disability prevents the person from doing the things most important to him or her	patient generated questionnaires (PGI, SEIQOL)

Testing the relevance of the ICIDH in Aboriginal communities

The first hurdle which has to be taken is with the definition of the concepts Impairment, Activities and Participation.

Participation

Many Aboriginal people have not liked the word 'handicap'. It will be important to discuss the old term, 'handicap', and the new term, 'participation', to find out:

- what is understood by the word handicap;
- what makes a person handicapped;
- if participation is understood in the same way as handicap;
- are there more people who have restrictions in participation than there are handicapped people in the community; and
- if participation is a concept which people are happier using in terms of themselves and other people.

Impairment

As already discussed, there are several problems with obtaining information on the number and extent of impairments. For example:

- some impairments may be so common in the community that they are expected and do not cause concern;
- different theories of illness causation may limit the degree to which some impairments are reported; and
- some impairments may be masked by the social setting and opportunities (ie. education and employment) that are available.

Activity

Activity is limited when '...the person, in the context of a health condition, has difficulty performing the activity or is unable to perform it at all...The norm here refers to a person without disablement' (ICIDH-2, 1997).

This would, on the surface, appear to be without problems, as it is a physical and observable phenomenon. However, the type of activities which are potentially available to a person are culturally dependent, as are the measurement of such activities. The difficulties in this area are emphasised by the problems with applying the SF-36 in Aboriginal communities. The SF-36 contains questions about climbing stairs and playing lawn bowls - activities which are likely to be inappropriate in the context of remote Aboriginal communities.

We therefore need to know what activities are potentially possible for people with impairments, living in designated communities.

Participation

Two potential problems with the participation domain have already been alluded to; one is that the domain does not refer to non-participation due to a person's culture etc. and the other is that it does not refer to voluntary non-participation. Ariotti's study mentioned voluntary non-participation due to shame in one's appearance. There is also the possibility, in the Aboriginal context, that the headings in Chapter 5 (education, work, leisure and spirituality) are concepts that are too diverse, and that spirituality is something that should be considered separately. The subjective nature of the

participation dimension and its relationship to the concept of quality of life have also been discussed.

While it is potentially possible to gather information about the number and type of impairments, and what restriction in activities these cause to Aboriginal people living in remote communities, the challenge remains to find information about the participation domain. Participation equates to what people want to do, and how they are prevented from doing these things, by their health condition. Obviously, what people want to do will be dependent to some degree on cultural norms of behaviour. But this is further complicated by the fact that the things that people want to achieve are changeable, and dependent on circumstances. The processes of adaptation, coping and changing expectations, all play a role in what a person considers to be the most important things in their life. For example, after an accident a person may substitute a more sedentary hobby for an active sport, and in time, derive equal satisfaction from it. Finally, as Ariotti's study emphasised, people in remote communities may not be aware of opportunities to increase their participation, and their goals and aspirations may change as knowledge of available aids and services increases.

These are difficult enough concepts to understand within our own culture. To try to understand them in an Aboriginal context would require a long period of interaction and participation in daily life to gain an understanding of what people thought were the most important things in their life. It would also require an understanding of the individual goals and aspirations of those people who have impairments.

Methodology

We have a very limited understanding of what concepts of health, quality of life and disability mean to Aboriginal people. Because of this, testing the ICIDH requires a very different approach to that which might be adopted in non-Indigenous communities. It is necessary to find out:

- how people with impairments are viewed by their community;
- what criteria is used to identify people with impairments;
- what activities are normal in the community (for example, the ability to drive a car may be meaningless in communities where there is very limited transport);
- what individuals regard as being important in their lives;
- what individuals feel that they cannot do because of their health condition;
- what contextual factors limit or prevent a person from achieving their aims; and
- what contextual factors could help a person achieve their aims.

The complexities of examining disability cross-culturally have already been stated, along with the necessity for long-term field work. I am planning to use the anthropological technique of participant observation in an attempt to find answers to these questions. It is necessary to spend an extended period in the field to develop relationships and trust with the members of the community. This is especially important when talking about issues as sensitive and personal as health and quality of life.

When I begin to have sufficient background knowledge to provide a basis for asking informed questions, I intend to supplement the information collected, with interviews and small group discussions. An approach such as this one demands the flexibility of the researcher, as the pace and timing of the research is largely dependent on the community itself.

Conclusions

Several authors have argued that Aboriginal people dislike the act of being singled out by a classification (Gething, 1994; Bostock, 1991), and that the word handicap is particularly disliked (Curry, 1993). It is possible that the new ICDH, with its neutral terms, and its universal focus which includes all people (not only those with disabilities) (ICIDH-2, 1997:8), may be seen as an improvement. This, however, will only be possible if ways are found to translate or explain the new concepts.

It is clear that a study to test the relevance of the ICDH must be long-term, as the researcher would have to be very familiar with the community to be aware of the following factors:

- the environment and setting in which people live and what impact this has on their participation;
- the effect of culture on the activities and participation dimensions; and
- the hopes and ambitions of individuals, in relation to the participation dimension.

Finally, we have to be very clear why we want to use the ICDH in Aboriginal communities. It may be very useful to have consistent definitions and to have a framework for understanding the effects of impairment on a person's quality of life, but what tangible benefits will this bring to individuals? And how do we explain these?

References

- Ariotti, L. J 1997, *'The Newly Planted Tree': an Exploration of Anangu Perceptions of Disability*, Master of Science Thesis, The Flinders University of South Australia.
- Australian Bureau of Statistics & Australian Institute of Health and Welfare 1997, *The Health and welfare of Australia's Aboriginal and Torres Strait Islander Peoples*, AGPS, Canberra.
- Berndt, R. M & Berndt, C. H 1964, *The World of the First Australians*, Sydney, Angus and Robertson.
- Bostock, L 1991, 'Access and equity for the doubly disadvantaged', *Aboriginal and Islander Health Worker Journal*, 15 (4): 10-15.
- Cowlshaw, G. K 1979, *'Woman's Realm: A Study of Socialisation, Sexuality and Reproduction among Australian Aborigines'*, PhD Thesis, University of Sydney.
- Curry, R, 1992, *'Needs Assessment Report: People with Handicaps and the Frail Aged in Five Aboriginal Communities'*, Department of Health, Housing and Community Services, Darwin.

- Elliot, D. M, 1994, '*Aboriginal perceptions of Disability and the formulation of an appropriate method of providing rehabilitation services to clients on remote communities*', Commonwealth Rehabilitation Service, Pilot Project Number 1, Darwin.
- Gething, L, 1994 'Aboriginality and Disability', *Aboriginal and Islander Health Worker Journal*, 18 (3): 29-34.
- Henderson, G and Gray, A, 1994 *The Tharawal Aboriginal Family Environmental Health Survey*, a report prepared for the Tharawal Aboriginal Health Services, Australian Institute of Aboriginal and Torres Strait Islander Studies and Research School of Social Science, The Australian National University.
- Hickey, A, Bury, G, O'Boyle, C, Bradley, F, O'Kelly, F and Shannon, W, 1996 'A new short form individual quality of life measure (SEIQOL-DW): application in a cohort of individuals with HIV/AIDS', *British Medical Journal*, 313:29-33.
- Honeyman, P. T and Jacobs, E. A. 1996, 'Effects of culture on back pain in Australian Aborigines', *Spine*, 21 (6):841-843.
- Kalberry, P. M. 1939, *Aboriginal Women, Sacred and Profane*, London, George Routledge and Sons Ltd.
- Meggitt, M. J. 1964, *Desert People*, Sydney, Angus and Robertson.
- O'Boyle, C. A, McGee, H, Hickey, A, O'Malley, K and Joyce, C. R. B. 1992, 'Individual quality of life in individuals undergoing hip replacement', *The Lancet*, 339:1088-1091.
- Reid, J. 1983, *Sorcerers and Healing Spirits, Continuity and Change in an Aboriginal Medical System*, Australian National university Press, Canberra.
- Ruta, D. A, Garrat, A. M, Leng, M, Russell, I. T and MacDonald, L. M 1994, 'A new approach to the measurement of quality of life, the Patient Generated Index', *Medical Care*, 32(11): 1109-1126.
- Ruta, D 1997, 'Managing and measuring health outcomes', paper presented to the Managing and Measuring Health Outcomes Conference, Canberra, 31 October.
- Taylor, J. C 1977, 'A pre-contact Aboriginal medical system on Cape York Peninsula', *Journal of Human Evolution*, 6:419-432.
- Thomson, N and Snow, C, 1994, *Disability and Handicap among Aborigines of the Taree Area of New South Wales*, Aboriginal and Torres Strait Islander Health Series, No.9, Australian Institute of Health and Welfare, AGPS, Canberra.
- Wimiydji and Peile, A. R, 1978, 'A desert Aborigines view of health and nutrition', *Journal of Anthropological Research*, 34:497-523.
- World Health Organization, 1997, *ICIDH-2: International Classification of Impairments, Activities and Participation*, Geneva.
- Zierch, T, 1990, 'The reintegration of Aboriginal children with significant physical disabilities into remote communities', *Australian Disability Review*, 3: 24-30

THE ABORIGINAL COMMUNITY CONTROLLED HEALTH SECTOR PERSPECTIVE ON THE COLLECTION AND USE OF ABORIGINAL HEALTH DATA AND ITS RELEVANCE FOR PEOPLE WITH A DISABILITY IN ABORIGINAL COMMUNITIES

By Pat Swan and John D.B Williams, NSW Aboriginal Health Resource Co-Operative Ltd (AHRC)

Introduction

On behalf of my colleague, Pat Swan, and all members of the NSW Aboriginal Health Resource Co-operative (AHRC), it is my privilege to thank the Ngunnawal people for the honour of being on their lands, and for the opportunity to attend this conference. This conference provides us with the opportunity to exchange insights and ideas and to share those spiritual values which underpin Aboriginal culture, and which can best direct our thoughts, as we seek to grapple with the dilemma of people living with disabilities in some of the most disadvantaged communities in this country.

In instances where I have capitalised the word 'Community', I am referring to the Aboriginal and Torres Strait Islander community.

The current situation

In his *Meares Oration* delivered in Perth in 1991, under the auspices of the Disability Advisory Council of Australia, Lester Bostock, a Bundjalung man from Northern NSW, spoke on the subject 'Access and Equity for People with a Double Disadvantage'. Following a statistical summary of the disparity in the health status between Aboriginal and non-Aboriginal Australians, well known to all the participants at this conference, he highlighted that :

There is very little reference material that categorises Aborigines as having some form of disability...Information about Aborigines seems to be hidden under the banner of the multi-cultural policies, and researchers and health workers have found it difficult to identify the Aborigines who are disabled.

Acknowledging some attempts by service providers to gather data on Aboriginal people with a disability, he commented that even these endeavours were besieged by funding restraints, and that together with the lack of service delivery, left many Aboriginal people with the perception that they have been excluded from service delivery.

Lester Bostock refers to the Sydney-based Aboriginal Medical Service paper *Aborigines and Disabilities*, and notes their health workers' assessment that within urban, rural and remote Aboriginal communities in NSW:

...many Aborigines with disabilities do not recognise that they are disabled, and Aborigines view themselves as a whole community and see such categories as attempts to erode their community solidarity and cultural identity.

Whilst the hardships that result from a lack of knowledge of, and about, the services, equipment and resources available to non-Aboriginal sections of the population are severe and onerous upon people with disabilities, their carers and the Community itself, this description has positive and profound significance because it demonstrates that the holistic view of Aboriginal health provides the ultimate for people with a disability - acceptance as equal members of, and as an integral part of, a supportive and caring community.

This particular characteristic of Aboriginal society is reflected by NACCHO in their understanding of Aboriginal health, which is defined as follows:

'Aboriginal health' means not just the physical well-being of an individual but refers to the social, emotional and cultural well-being of the whole Community in which each individual is able to achieve their full potential as a human being thereby bringing about the total well-being of their Community. It is a whole of life view and includes the cyclical concept of life-death-life.

Services for people with a disability quite naturally fall within the functions of an integrated Aboriginal community controlled health service, and again, the NACCHO definition is helpful as we address the subject of disability within the Aboriginal and Torres Strait Islander communities. 'Aboriginal health-related services' are:

... those services covered by the Aboriginal holistic definition of health including, but not restricted to, such services as health promotions and disease prevention services, substance misuse, mens' and womens' health, specialised services to children and the aged, *services for people with disabilities*, mental health services, dental care, clinical and hospital services and those services addressing, as well as seeking the amelioration of, poverty within Aboriginal communities.

It is considered incumbent upon those statisticians and epidemiologists who offer their professional expertise to assist Aboriginal communities in monitoring access and equity for people living with a disability, and researching collected data, to grasp the important maxim that the provision of services for, and the collection of health information data on, Aboriginal and Torres Strait Islander people with a disability, must be seen in the context of an integrated, supportive and caring community.

The World Health Organization has conducted surveys of various populations and have estimated that ten percent (10%) of any population is living with some kind of disability. The variables which affect such an estimate are complex and sometimes the result of parochial customs, affluence, subjectivism or perhaps the failure to identify, or reluctance to acknowledge, non-visible disabilities. This is an area best left to the professional data analysts and statisticians. This conference is an opportunity for those actively involved in health service delivery, to pool experiences and insights, so that together, we can redress the scant details available on disability within indigenous communities in Australia, and provide more definitive and perceptive tools to more closely reflect the actual situation, and to minimise underestimation.

Southern African nations and disability

It was not surprising that the conclusions of the ten constituent African nations of the South African Federation of the Disabled (SAFOD), in their analysis of disability throughout their part of the African continent, closely resemble the situation for people with a disability in Aboriginal and Torres Strait Islander communities. Their study suggests that there is a positive correlation between underdevelopment and disability. Underdevelopment was described as a state of dependency, with static, shrinking, contracting communities which are ravaged by poverty, economic isolation and marginalisation, poor health services, inadequate housing, contaminated water and poor sanitation, high levels of unemployment, lack of resources, lack of gainful employment

and lack of employment generating opportunities. All these experiences are the symptoms of former colonial regimes which concentrated wealth in the hands of non-indigenous settlers, leaving the local indigenous peoples in poverty. The report identified land alienation as one of the major causes of underdevelopment as well as being a symptom of underdevelopment.

It is against this backdrop that the statement is made that there are more people with a disability amongst the underdeveloped and disadvantaged of Southern Africa. This paralysis is compounded by the concomitant negative attitudes from the public, government and family; stereotyped attitudes which see people with a disability as different from people with no disability, and the numerous deprivations which disability groups have challenged over the years. Whilst the report has a positive note to combat these aberrations of human rights and justice, it notes that people with a disability face numerous problems e.g transportation shortage, and concludes that the life expectancy of disadvantaged persons with a disability is shortened.

The predicament and experiences of Aboriginal and Torres Strait Islander peoples in this country closely parallel those of many Southern Africans. Specific needs can be identified, for example, the need for services for carers of Indigenous people with a disability, compared with the services and benefits available to carers in the non-Aboriginal community. This is a specific area where data analysis could assist. Of significant benefit, would be the collection and analysis of data on the level of awareness of support services, and other issues involving access and equity.

However, most relevant to the indigenous peoples in this country, and most poignant of all in the shared African and Australian experience of colonialism, is the dispossession of land. The timely national discussion on the Wik Bill, before the Australian national parliament, is basically about dispossession of land and the fact that land is an indispensable part of Aboriginal culture and spirituality; so necessary for the healing of Aboriginal communities. As Bostock recognised, in addition to the more recognised disabilities and handicaps which result from physical, mental and intellectual impairments, and their various levels of severity, 'there is another type of disability and that is cultural disability caused by cultural dissemination.'

The NACCHO definition has insightfully described this area of ill-health as: 'Socio-somatic illness' and defines it as follows:

... those physical ailments, bodily disorders and psychological or mental conditions which impair the health of Aboriginal people and the well-being of Aboriginal communities resulting directly or indirectly from sociological disadvantage; economic deprivation; racism; assimilationist legislation, policies and practices; unemployment; lack of housing; dispossession; alienation from land; forced separation from parents, children, families and communities; and other traumas, which impinge and have impinged upon Aboriginal people since dispossession.'

The recent national attention given to the stolen generations and the *Inquiry into the Removal of Aboriginal and Torres Strait Islander Children from their Parents* has revealed how deep this crippling trauma has been for Aboriginal people, families and communities. The legacy of mental anguish and suffering has touched every segment of Aboriginal life, without a family left unscathed. It is difficult to comprehend the extent of suffering, which will place onerous demands upon the most competent psychiatrist, yet

the Royal College of Psychiatrists has offered and provided services *pro bono* in an attempt to combat the psychological devastation which has been passed on to successive generations.

In efforts to address disability amongst the indigenous peoples of this country any attempt to quantify and interpret data to detect accurate levels of disability would be suspect without due recognition of this travesty of justice. Equally essential is the need to acknowledge the inextricable link between land and the very psyche and spirituality of Aboriginal people and to acknowledge the disabling consequences that non-recognition of this pivotal point has had in undermining the health and well-being of the longest surviving indigenous culture in the world.

The task of more accurately detecting and analysing the extent of disability within indigenous communities, through the development of appropriate data collecting techniques and procedures, will challenge the most competent statistician. There is a real need to sensitively tread, where the Community alone can direct.

It is this very understanding of Indigenous communities which can best introduce the Aboriginal community controlled health sector's position on data collection and use.

The Aboriginal community controlled holistic understanding of health determines that the collection of data on people with disabilities cannot be isolated from the wider discipline and task of collecting health data on Aboriginal people. The Framework Agreements, entered into by the Commonwealth Minister for Health and most States and Territory governments with peak State and Territory Aboriginal community controlled bodies affiliated with NACCHO, have provisions for the development of 'culturally sensitive and ethically sound, privacy and confidentiality protocols for the routine collection of standardised data on Aboriginal and Torres Strait Islander health.'

These protocols will recognise ownership of data by Aboriginal and Torres Strait Islander peoples and have clear guidelines on the collection and use of the data. The indigenous peoples' control of their data is clearly recognised in the Framework Agreements' provisions which require the owner's consent before there can be any change in use of data.

All the expected standards which are usually associated with data collection and their use will apply, with safeguards for individual and Community confidentiality and anonymity; informed consent will be required; terms for data security, reporting back and specified use; approval of questionnaires; terms for destruction and return of data; and terms addressing the publication of materials. The employment of Aboriginal people, where possible, in data related projects, and the adequate repayment for expenses, together with due recognition for services rendered, will all be included in a required written Agreement. Relevant definitive documentation outlining ethical provisions for the collection and use of health data on Aboriginal health, from the scientific, departmental and Aboriginal community controlled health sectors, can be found in Appendix 1 on Pages 98-107.

In an attempt to carry out the recommendations in the National Aboriginal Health Strategy which relate to the collection and use of data, NACCHO has approved a model which will expedite data collection, while at the same time ensuring that Community ownership, control and participation at each level the Community controlled sector,

occurs. This will be achieved through a Memorandum of Understanding or by a Regional Agreement being entered into.

This procedure will encourage collection and wide participation while at the same time allow culturally sensitive matters to be retained by the Community concerned. At each stage of the process reciprocal sharing of information will take place at the regional, State and national levels with mainstream services.

The varied and demanding task ahead for epidemiologists and statisticians will be greatly assisted by this national co-operation while at the same time Communities can be reassured that adequate measures are in place to protect confidential and sensitive matters, with the provision for Community anonymity.

As the new program of collecting data on people with disabilities commences, Aboriginal communities will willingly assist knowing that they will be 'involved in each stage of development of Aboriginal health statistics' as recommended by the *Recommendations of the Royal Commission into Aboriginal Deaths in Custody*. Their participation in this program will assist those in greatest need; 'the double disadvantaged' that Lester Bostock refers to, and at the same time, protect individual privacy and guard against further cultural encroachment.

APPENDIX 1

DEFINITIVE DOCUMENTS FOR ETHICAL PROVISIONS IN THE COLLECTION AND USE OF DATA ON ABORIGINAL HEALTH

Documents

National Health and Medical Research Council (NHMRC): Statement on Scientific Practice

National Health and Medical Research Council (NHMRC): Statement on Human Experimentation

National Health & Medical Research Council (NHMRC): Health Australia Project Discussion Paper, August 1996

National Aboriginal Health Strategy (NAHS)

National Aboriginal and Islander Health Organisation (NAIHO), Report on the National Workshop on Ethics of Research in Aboriginal Health

Recommendations of the Royal Commission into Aboriginal Deaths in Custody

Memorandum of Understanding between ATSIC and the Commonwealth Minister for Health and Family Services

Framework Agreement

NHMRC Statement on Scientific Practice

Ethical commitment

'Research workers should only participate in work which conforms to accepted ethical standards and which they are competent to perform...'

Confidentiality

If data of a confidential nature are obtained, for example, from individual patient records or from certain questionnaires, confidentiality must be observed and research workers must not use such information for their own personal advantage or that of a third party....

As is the case with medical research, this NHMRC statement recommends the establishment of appropriate confidentiality protocols for receiving complaints about the health data information process, as well as timely informative reports on the matters raised.

Staff engaged in collecting data must observe that the data is only used for the purpose agreed upon and no other application for the data is permissible, or transfer to a third party is permitted, without the expressed consent of the contributors.

Secrecy

'Secrecy may also be necessary for a limited period in the case of contracted research.'

Data gathering, storage and retention

The NHMRC recommends that data should be retained within the department or research unit within which they were generated. From a practical basis, some information flow may be necessary, however, this does not negate the need to trace and monitor information flow of data, and for the providers, at the appropriate level, to be kept informed at all times. The document makes recommendations for appropriate storage and recording.

Disclosure of potential conflicts of interest

To ensure that confidence is given to the data assembled on Aboriginal health it is imperative that any conflict of interest be declared and acknowledged, no matter how minimal.

Concerning the emphasis for complete disclosure of any conflict of interest in the general field of medical research, it is considered prudent and necessary that, from an Aboriginal community perspective, these principles should also be incumbent upon contributing parties to health data information mechanisms.

NHMRC: Statement on Human Experimentation

(To be read in conjunction with the *Supplementary Notes*, especially *Supplementary Note 6 - Epidemiological Research*)

Researchers have ethical and legal responsibilities towards those they are researching and should carefully follow clear guidelines. Several of these apply with regard to the collection of data on Aboriginal health.

Informed consent

NHMRC *Statement on Human Experimentation* provides that consent must be in writing unless there are good reasons to the contrary, and in the case of the latter, documents of the circumstances should be recorded. For the collecting of data verbal authorisation is inappropriate.

Provision to withdraw consent

It is recommended that informed consent for medical research is always qualified by the right of the individual or group to withdraw and no longer participate. Accordingly, the

collection of raw data for epidemiological analysis in Aboriginal health should be viewed with similar provisions, and participants should be free of duress and mandatory reporting requirements.

Ethics committees

In medical research in general, the NHMRC recommends that institutions establish ethics committees. Whilst similar bodies could be developed for epidemiology and data collection, the Aboriginal community at each level - local, state and national, would provide the definitive words on ethical matters. Some State bodies affiliated with NACCHO have their own ethics committees which are used by their constituent member organisations. Such bodies would naturally be part of any analysis or review of ethical and cultural matters related to data collection and its use.

NHMRC: Health Australia Project Discussion Paper, August 1996

Relevant recommendations within this publication by the NH&MRC under the topic 'Monitoring and Surveillance' are as follows:

... designated funding be provided to enable the Australian Bureau of Statistics to continue to conduct regular national health and risk factor surveys for Aboriginal and Torres Strait Islander peoples.

and

... the Australian Institute of Health and Welfare work with Aboriginal and Torres Strait Islander communities to develop a plan to improve all aspects of information about their health and access to health services.

NHMRC: Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Health Research

Whilst requiring further refinement from an Aboriginal community perspective the document breaks new ground in the field and provides specific details for appropriate standards to be in place before any research can be considered.

Consultation

The importance of community consultation is acknowledged by the Medical Research Ethics Committee of the NHMRC which recognised that there was:

... a lack of appreciation of ethical issues relevant to research involving Aboriginal and Torres Strait Islander people, which led to:

advice and approval of Aboriginal or Torres Strait Islander individuals in Government departments being accepted as a substitute for proper community consultations and negotiations; and

lesser standards for obtaining consent among disadvantaged Aboriginal and Torres Strait Islander communities.'

Among its salient points, the *Guidelines* document provides content for its expressed concern for Aboriginal community involvement and participation. It also includes recommendations which are relevant to the collection of Aboriginal health information data for epidemiological and bio-statistical purposes.

- 1 In the preparation of the research proposal, the researcher has sought advice not only from State, Territory and Federal Aboriginal and Torres Strait Islander Health agencies, but also from local community controlled Aboriginal and Torres Strait Islander health services and agencies.
- 2 The Aboriginal and Torres Strait Islander community, or appropriate community controlled agency able to represent the Aboriginal and Torres Strait Islander Group which is the focus or context of research, has indicated that the research being proposed will be potentially useful to the community in particular or Aboriginal and Torres Strait Islanders in general, and will be conducted in a way that is sensitive to the cultural and political situation of the community.
- 3 The researcher has obtained written documentation of consent from the communities in which it is proposed to conduct research and where this has not been possible, the reasons should be obtained.

There follows specific tangible provisions which ensure informed consent from the Aboriginal communities.

Adequate time-frame

One such provision is to remedy the perennial difficulty Aboriginal communities have experienced across the whole country in not being given sufficient time to adequately respond to given requests. This has direct application for data collection with its required documentation, questionnaires and responses. Informed consent includes documented evidence which demonstrates that involvement has taken place which enables 'the allowance of sufficient time for the community and the individuals concerned to assimilate and respond to the information offered'.

Community involvement

The document provides a very positive and workable basis for ensuring informed consent from the Aboriginal community, stressing the indispensable requirement for genuine Community involvement. The National Aboriginal Health Strategy (NAHS) has documented former procedures which reduced community consultation to mere information sessions. In essence, appropriate Community consultation incorporates 'negotiation' which implies mutual agreement and informed discussion.

The researcher must recognise the right of the community to request further information about aspects of ongoing research, and accept that changes in research protocols, procedures or methodologies will require further negotiations with the Community and consent for that change by the Community, or an agency nominated by the Community. The Institutional Ethics Committee (IEC) must also be notified and be given the opportunity to approve changes to the research protocol.

Local community ownership and consent

It is also incumbent upon the data requesting body to acknowledge the necessity to seek the consent of each participating Aboriginal community.

Ownership and publication of data

The NHMRC Guidelines on 'Ownership and Publication of Data' moves the debate a long way towards the Community position. One of its recommendations for the ownership of data is as follows:

If there is any reason to expect that there may be a misunderstanding between researchers and Aboriginal and Torres Strait Islander research subjects over the conduct of research, the ownership of raw data or the rights to publication of research findings, these matters should be discussed and negotiated and preferably agreed upon by both parties before the research begins.

From an Aboriginal community perspective it is considered deficient that provision for negotiation is merely 'preferable' and not mandatory. Failure to secure an agreement for the collection of data precludes any use or publication of related research and is inconsistent with recommendations made and assurances agreed between interested parties.

It is also recommended within this NHMRC document that any publication following analysis of data be reported to the 'community as a whole' with details of an individual nature being confidentially conveyed to the participants.

From an Aboriginal cultural perspective, the publication of findings would need to be reported to the body providing the information - local, state or national, rather than an all inclusive statement which does not constitute informed consent.

National Aboriginal Health Strategy (NAHS)

The National Aboriginal Health Strategy contains an entire chapter on the specific issues of data systems; and evaluation and monitoring of the prevailing condition of Aboriginal health.

Throughout the whole document, the place of the Aboriginal community is central in working through both its own health services, and in co-operation with Commonwealth and State mainstream health programs.

Monitoring and evaluation

Monitoring and evaluation by the community 'serve a useful purpose in promoting greater participation in the provision of Primary Health Care.'

Unrealistic and onerous demands

Performance Indicators should not make 'unrealistic demands' upon an organisation which provide 'little information useful in improving services delivered'.

Cause for concern

Similar to the acknowledgement in the NHMRC Guidelines, reference is made to past practices which have given rise to concern.

Communities have often had good reason to see the process of monitoring and evaluation as a means by which government might gather information about a community without that community's consent and/or the means by which government might coerce a community into adopting standards it might otherwise wish to reject.

Centrality of the Aboriginal community

The centrality of the Aboriginal Community in all matters relating to its own health is paramount throughout the Strategy. The involvement of Aboriginal communities in the process itself is seen as 'integral' to an objective analysis of progress in Aboriginal health, in identifying new goals and any necessary policy adaptation and revision. It is also the basis for providing an informed position, in the assessment role it shares with the Commission and the Department of Health, for 'the establishment of new services and facilities in response to changing needs.'

Collection of data

The Strategy recognised the role for:

National, State and Territory agencies' involvement in the collection of data information on Aboriginal health and their need for a more adequate monitoring of mainstream services and improvement in the provision and quality of data collection information systems.

The NAHS Working Party Report recommended:

That an appropriate level of resources be made available to the Australian Institute of Health to enable comprehensive Aboriginal health statistics data collection, analysis and reporting.

Aboriginal community involvement in monitoring and evaluation

The Strategy recognises the Aboriginal community's involvement in monitoring and evaluating Primary Health Care. It stresses the need to have data collections and analyses at the service delivery level, and sufficient resources (to Community Health Services) to develop and operate detailed monitoring and evaluation.

The Strategy acknowledges the progress in data systems within certain Aboriginal community controlled health services and considers that:

Responsibility for monitoring and evaluation falls on those individuals or groups most closely concerned with the delivery of service. This requires that at each level of care... mechanisms should be developed... within each level of the health system. It also applies to the evaluation and monitoring of the policy function and to primary, secondary and tertiary levels of care.

Information collection

The Strategy considers that the essential attributes to the process are 'Relevance, adequacy, progress, efficiency, effectiveness quality and impact.' However, it considers that 'It is also necessary to have a clear picture of how and by whom the information is to be used'. Further:

... the strengthening of the information capacities of primary health care providers is fundamental to improved monitoring and evaluation. The enhancing of such capacities at the community level will assist in terms of program budgeting and the development of valid and relevant performance indicators... Aboriginal health services should be encouraged individually and collectively to develop and prepare information and other evaluative reports as part of their management system.

National Aboriginal & Islander Health Organisation (NAIHO): Report on the National Workshop on Ethics of Research in Aboriginal Health

The Report mentions the importance of Community involvement at each stage of research and related data collection process.

The initial stages of research and data collection have to conform to stringent guidelines that meet Aboriginal community approval. Obtaining ethical approval from the Community controlled sector is spelt out with clear expectations about what constitutes proper consultation. The process of 'consultation/negotiation' has to be clearly identified to ensure that proper discussion occurs, and the control of these discussions is vested in the Communities. Provision must be made to also ensure that appropriate cultural protocols and procedures are in place. It is clearly stated that approval obtained from Aboriginal people in government departments is no substitute for proper community consultation/negotiations.

Communication and consent

The following definition was given as the accepted text from the workshop which developed the Report.

Communities must be provided with all the relevant information and explanations on the intent, process and methodology, evaluation and potential use of any research proposal.

Researchers must comply with any request for further information from relevant community controlled agencies associated with the research proposal.

Community process of decision making will reflect varying social and cultural values. In obtaining the consent of communities to research, researchers must respect the Aboriginal community's process of decision making.

Another relevant matter, with regard to the collection of data information for research purposes, is that the Community be allowed sufficient time to adequately examine all proposals.

Ownership and publication of material

The Report also covers publication and ownership of material and the on-going role in monitoring the implementation of research, all of which are considered of vital importance to local Aboriginal communities. This reflects the current position of NACCHO, with the document being attached to the NHMRC Guidelines. Some of the specific recommendations on the ownership and publication of materials are that:

Research material and data shall remain the property of the Community. The Community retains the right to censor research of a sensitive nature. Prior to publication or other use of research materials or Reports, the approval of the relevant controlled agency is required; and

...in preparing acknowledgement of research, the proper accreditation of participation and assistance of Aboriginal individuals, communities and their agencies should be noted.

Other recommendations cover the assurances for privacy and non-identification in research which are equally binding in any collection of data on Aboriginal health or epidemiological study.

Exploitation of community resources

As other primary documents have recognised, there should be no imposition upon the Aboriginal community controlled health sector to be involved in processes that are not adequately funded or resourced.

Associated costs incurred by Aboriginal communities and Aboriginal community controlled organisations should be fully reimbursed.

In seeking the co-operation of Aboriginal communities and local community controlled agencies, [researchers] must provide reimbursement of any cost incurred which relates, directly or indirectly, to programs of research. Such costs could include telephones, transport, freight, gas and water, accommodation, supervision costs and wages of assistants and interpreters.

Employment of Aboriginal people in research projects

The recommendation that Aboriginal people be employed in research projects is also within the context of ethical matters associated with conducting research on Aboriginal and Torres Strait Islander health.

In many circumstances the employment of community members will aid the Researcher and improve the quality of communication and ultimately strengthen the initiative.

Researchers, where local community controlled agencies believe it necessary, must provide for the employment of local Aboriginal co-investigators.

Ongoing review of ethical standards

The NAIHO Report realistically appraises ethical standards in Aboriginal health and recommends that:

Ethics Committees and the relevant community controlled agencies have an ongoing responsibility to ensure compliance with appropriate ethical standards.

The thrust of the remainder of this section of the Report relates to procedures for research projects and practical recommendations for administering related funds, but the introductory comment, sighted above, is very relevant to the Aboriginal health information process, and requires specific inclusion in any protocols for ethical standards.

In light of more recent legislative developments, caution should be given to the role of ethics committees which can, under certain conditions, negate the Information Privacy Provisions within the Privacy Act. Whilst they make an important contribution in the field, ethics committees should not be seen as a substitute for the Aboriginal community decision making process, and ideally, should work in association with Aboriginal community health organisations.

It is for this reason that the Community itself is considered to be the determining body in matters relating to Aboriginal health information, rather than any national, State or

Territory ethics committee. State and Territory affiliated bodies of NACCHO do have valuable ethics committees but the underlying principle upon which they operate is the inviolate and undisputed position of the Aboriginal community itself to alone consider research into Aboriginal health.

Recommendations of the Royal Commission into Aboriginal Deaths in Custody

Recommendation 270

Recommendation 270 states that:

- a) Aboriginal people be involved in *each stage of development* of Aboriginal health statistics; and
- b) appropriate Aboriginal health advisory bodies (such as the Council of Aboriginal Health) consider developing an expanded role in this area, perhaps in an advisory capacity to the Australian Institute of Health and Welfare, and that the aim of this involvement should be to ensure that priority is given to the collection, analysis, dissemination and use of Aboriginal Health Statistics most relevant to Aboriginal health development.

Memorandum of Understanding between ATSIC and the Commonwealth Minister for Health and Family Services

A definitive document which underpins the implementation and procedures for the collection of statistical data, for information on Aboriginal health is the *Memorandum of Understanding between ATSIC and the Commonwealth Minister for Health and Family Services*. This document, the instrument which facilitated the transition between the Department and the Commission for carriage of the Aboriginal health portfolio, is valid until the 30th June 1999. It also incorporates an important ongoing role for the Commission in the collection of data on Aboriginal health.

Germane to the process of collecting and assessing statistical data on Aboriginal health, the following provisions appear relevant from an Aboriginal community perspective.

3.1.1 The Commission has statutory responsibilities to:

- (i) monitor the effectiveness of programs for Aboriginal and Torres Strait Islanders, including those programs to be conducted through the Department;

3.1.5 The Commission will assist the Department by providing access to any data collected on the impact of the activities undertaken by the Commission which may have relevance to health outcomes or to the planning and delivery of primary health care services.

3.3.3 The Department will be responsible, in consultation with NACCHO, ATSIC, the National Health and Medical Research Council and other health professional organisations for the development of appropriate standards for the delivery of health services, as well as mechanisms which meet the needs of both the Commonwealth and the Services for monitoring the effectiveness of health services.

3.3.5 To ensure effective co-ordination in the delivery of services, the Department will develop mechanisms to involve the Commission in the planning and priority setting for health services at the National and Regional level. Local Community controlled

services and NACCHO will also be invited to participate in such consultative mechanisms as appropriate.

3.3.8 The Department will consult with the Commission on the development of any data collections on primary health services and will provide the Commission with access to the aggregated data, as it relates to the delivery of environmental health programs provided by the Commission.

Framework Agreement

The parties to the *Framework Agreement*, being the Commonwealth of Australia and the respective States and Territories agree, in partnership with ATSIC, NACCHO and the relevant State and Territory peak bodies affiliated with NACCHO, to:

establish culturally sensitive and ethically sound, privacy and confidentiality protocols for the routine collection of standardised data of Aboriginal and Torres Strait Islander health. These protocols are to recognise Aboriginal and Torres Strait Islander ownership of the data including clarity about the collection and use of data. Any change in the use of the data will require agreement from the owners of the data;

(Framework Agreement 3.12)

improve the quality of relevant data available on the provision of mainstream health services to, and utilisation of mainstream health services by, Aboriginal and Torres Strait Islander peoples;

(Framework Agreement 3.13)

develop appropriate health outcome indicators to measure progress in improving the health of Aboriginal and Torres Strait Islander peoples; and

develop a mechanism to report specifically on health outcome indicators in (a) above.

(Framework Agreement 3.14)

APPENDIX 2

DEFINITIONS OF COMMON CONCEPTS USED IN DATA COLLECTION ON ABORIGINAL HEALTH

Aboriginal health

'Aboriginal health' means not just the physical wellbeing of an individual but refers to the social, emotional and cultural wellbeing of the whole community in which each individual is able to achieve their full potential as a human being thereby bringing about the total wellbeing of their community. It is a whole-of-life view and includes the cyclical concept of life-death-life.

NACCHO Memorandum and Articles of Association

Aboriginal health-related services

'Aboriginal health related services' means those services covered by the Aboriginal holistic definition of health including, but not restricted to, such services as health promotions and disease prevention services, substance misuse, men's and women's health, specialised services to children and the aged, services for people with disabilities, mental health services, dental care, clinical and hospital services and those services addressing, as well as seeking the amelioration of, poverty within Aboriginal communities.

NACCHO Memorandum and Articles of Association

Community control

'Community control' - the process which allows the local Aboriginal community to be involved in its affairs in accordance with whatever protocols or procedures are determined by the Community. The term Aboriginal Community Control has its genesis in Aboriginal peoples' right to self-determination.

NACCHO Memorandum and Articles of Association

Community information

'Community information' - any data and information that can be linked to an identifiable Community, whether that Community is identified directly or indirectly by reference to any combination or attributes which make possible their identification.

[Note: This definition applies both to information provided for which identification is not an issue or when specific prohibition of community identification is a term within a free and informed consent agreement.]

Confidentiality

'Confidentiality' - the characteristic of data and information being disclosed only to authorised persons, entities and processes at authorised times and in the authorised manner agreed upon at the time of free and informed consent.

Data

'Data' - a representation of facts, concepts, information, questionnaires, summaries, graphs, tables or instructions in a formalised manner suitable for communication, interpretation or processing by personnel or by automatic means which relate to details

on the health of Aboriginal communities provided by those Communities or their representative bodies and agencies.

De-identified data

'De-identified data' - data where the personal identifiers, or in certain circumstances the particular Community identifiers, have been stripped or altered to render the identification of the subject or Community concerned improbable.

'Derived information' - where multiple databanks exist, the ethical protocols inherent within this document shall apply to any derived information obtained or inferred as a result of combinations of such information.

Disclosure

'Disclosure' - any access to or use of personal or Community information by a third party.

Duty of care

'Duty of care' - a duty of care exists wherever a health care professional or health care employee accepts responsibility for the collection, analysis and use of data, during which period the said persons are entrusted with a moral, ethical and legal responsibility to ensure that, first and foremost, the best interests of the Aboriginal community are served and the terms of reference for free and informed consent are complied with.

Information management

'Information management' - unless the context otherwise determines, means those necessary functions and/or related ethical issues surrounding the collection, ownership, monitoring, storage, archiving, accessing, releasing, destruction, evaluating, reporting, analysing, publishing and use of health information on Aboriginal people and those issues necessary to ensure security, confidentiality and privacy of health information as well as those mechanisms necessary to appropriately deal with complaints and to mediate disputes between concerned or aggrieved parties.

Information privacy

'Information privacy' - the right of an individual person within a democratic society, and in certain specified circumstances the rights of an individual Aboriginal community, to control, respectively, the dissemination of personal and community identifying information about themselves.

Information system

'Information system' - computers, communication facilities, computer and communication networks and: data and information that may be stored, processed, retrieved or transmitted by them, including programs, specifications and procedures for their operation, use and maintenance.

Integrity

'Integrity' - the characteristic of data and information being accurate, complete and the preservation of accuracy and completeness.

Personal information

'Personal information' - any data and information that can be linked to an identifiable person, whether that person is identified directly or indirectly by reference to any combination or attributes which make possible their identification.

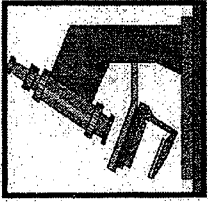
Repository body

'Repository body' - the organisation, department or agency which has responsibility for the receipt of, protection, analysis and use of data within a filing system or within a databank containing data.

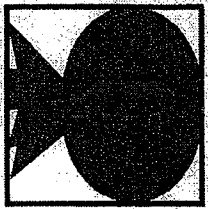
Third party

'Third party' - (with respect to the disclosure of personal information) a person, being neither the subject of the data to be disclosed, nor the subject's health care provider, and, (in certain specified circumstances with respect to the disclosure of Community information) being neither the Community of the data to be disclosed, nor the Community's Aboriginal community controlled health service.

REPORTING MECHANISMS FOR THE COLLECTION OF ABORIGINAL HEALTH INFORMATION, SERVICE ACTIVITY, FINANCIAL & ADMINISTRATIVE REPORTING WITHIN ABORIGINAL COMMUNITY CONTROLLED HEALTH SERVICES



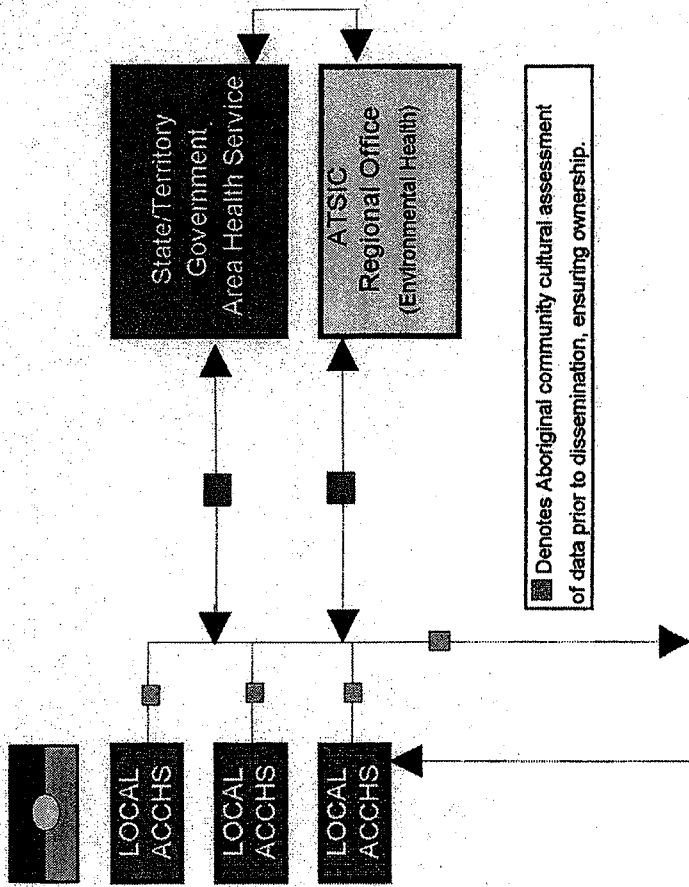
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(Scientific/Medical)



LOCAL PERFORMANCE INDICATORS
(Administrative/Financial)

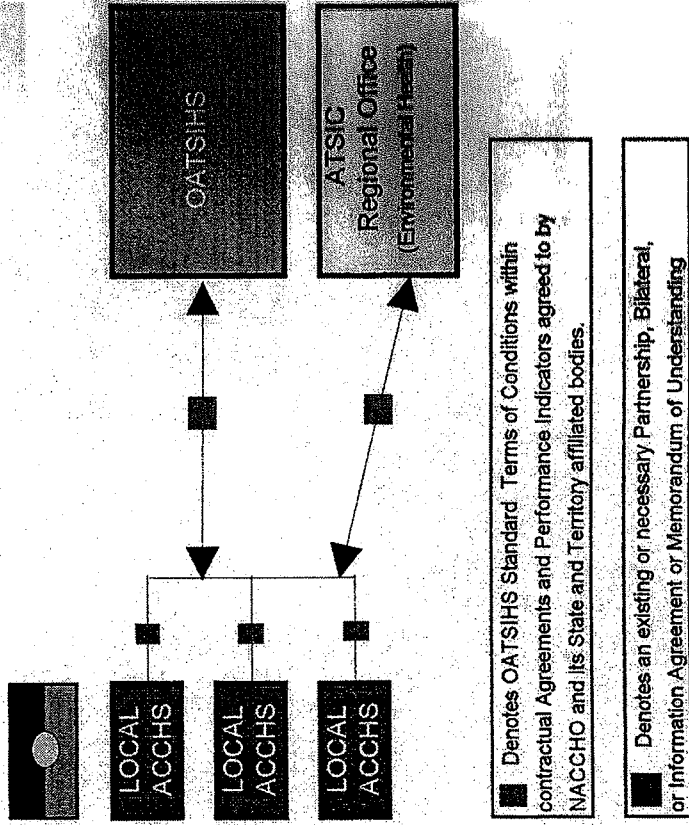
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STATISTICAL DATA
LOCAL AND REGIONAL LEVEL

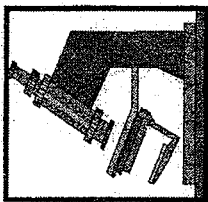


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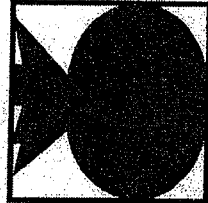
ADMINISTRATIVE & FINANCIAL REPORTING
LOCAL AND REGIONAL LEVEL



REPORTING MECHANISMS FOR THE COLLECTION OF ABORIGINAL HEALTH INFORMATION, SERVICE ACTIVITY, FINANCIAL & ADMINISTRATIVE REPORTING WITHIN ABORIGINAL COMMUNITY CONTROLLED HEALTH SERVICES



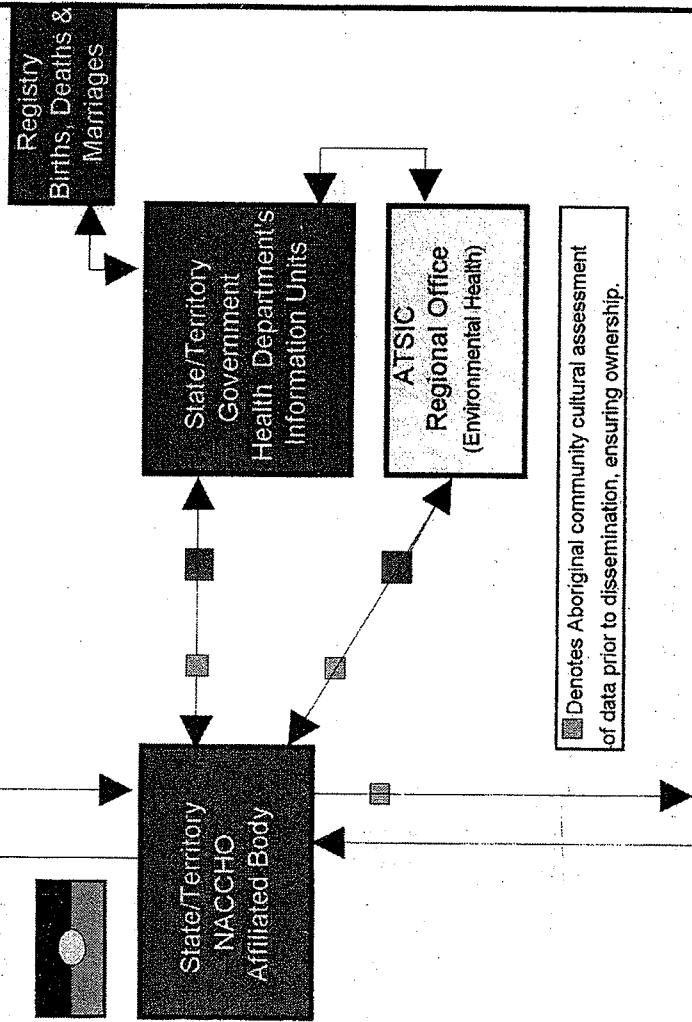
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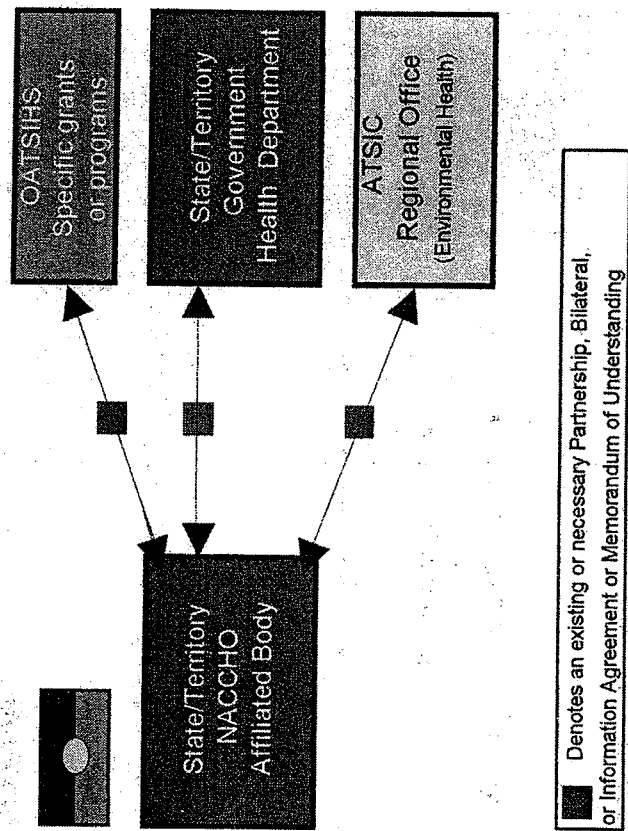
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STATISTICAL DATA STATE OR TERRITORY LEVEL

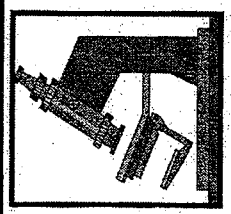


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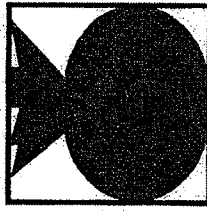
FINANCIAL ACCOUNTABILITY, AUDIT & GRANT ACQUITTAL STATE OR TERRITORY LEVEL



REPORTING MECHANISMS FOR THE COLLECTION OF ABORIGINAL HEALTH INFORMATION, SERVICE ACTIVITY, FINANCIAL & ADMINISTRATIVE REPORTING WITHIN ABORIGINAL COMMUNITY CONTROLLED HEALTH SERVICES



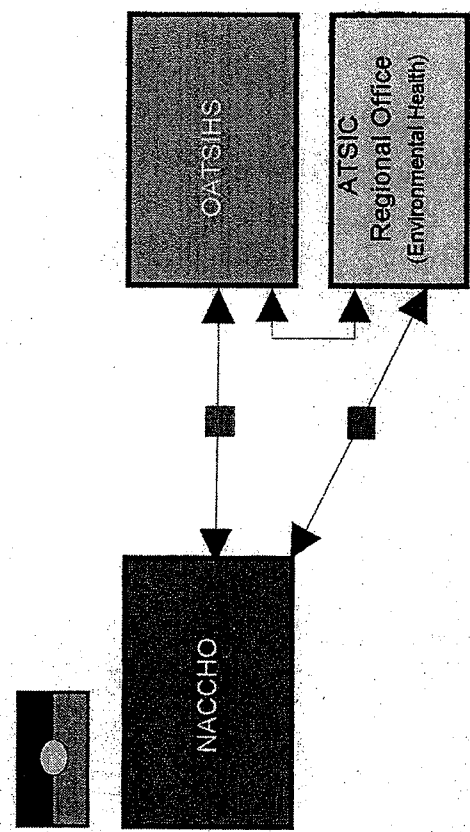
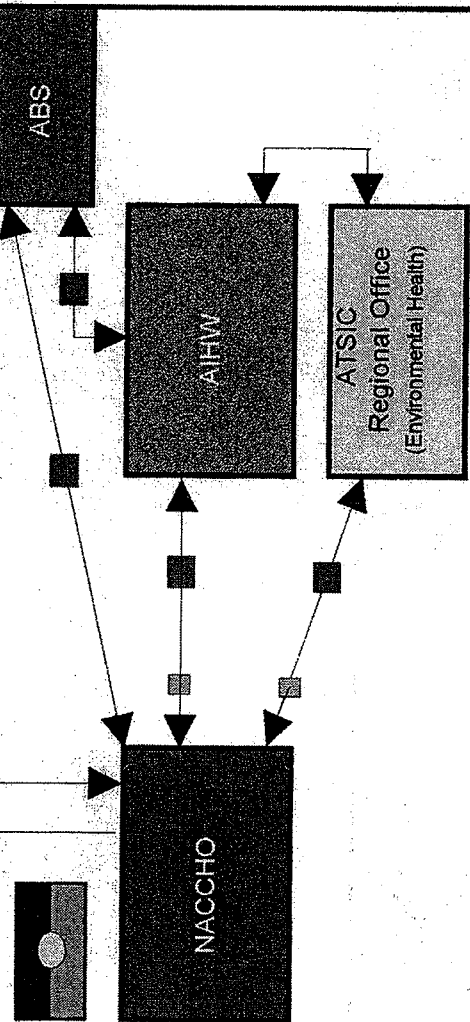
HEALTH INFORMATION SYSTEMS
(Scientific/Medical)



FINANCIAL REPORTING
(Administrative/Financial)

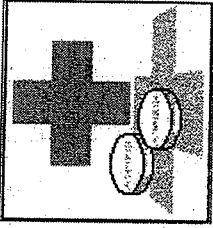
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STATISTICAL DATA
NATIONAL LEVEL

3
FINANCIAL ACCOUNTABILITY, AUDIT & GRANT ACQUITTAL
NATIONAL LEVEL



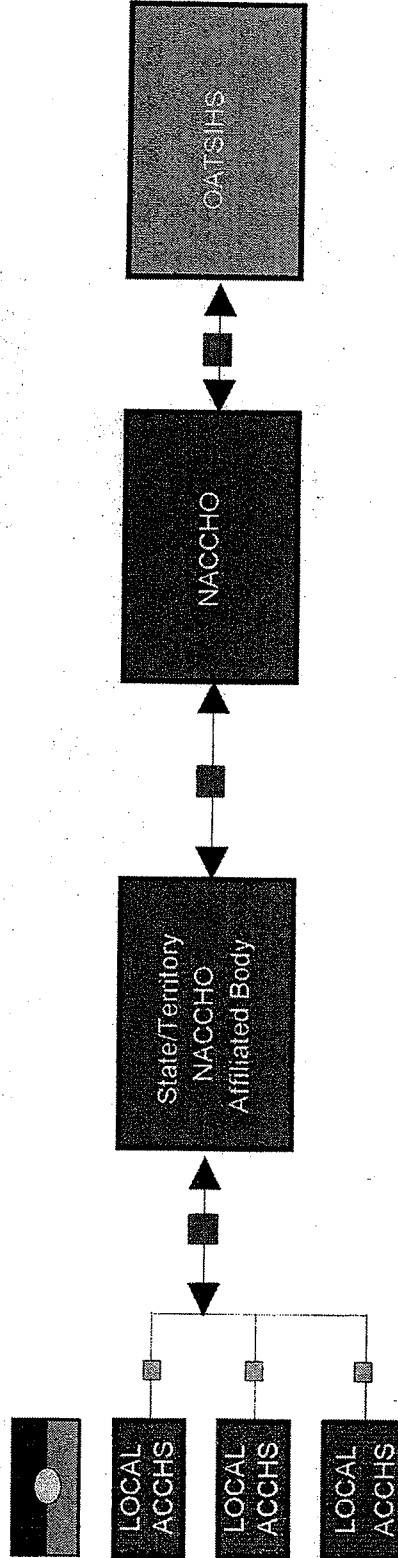
LOCAL PERFORMANCE INDICATORS

SERVICE ACTIVITY REPORTING



4

LOCAL ABORIGINAL COMMUNITY CONTROLLED HEALTH SERVICES



Denotes Aboriginal community cultural assessment of data prior to dissemination, ensuring ownership.

Denotes an existing or necessary Partnership, Bilateral, or Information Agreement or Memorandum of Understanding